

WHOLISTIC APPROACH TO THE DIFFERENTLY ABLED



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Good wishes
and grateful thanks to Mr. Francis
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NATIONAL CONSULTATION

ON

WHOLISTIC APPROACH TO THE DIFFERENTLY ABLED

Date : 27 Nov. — 1 Dec., 1995

**Venue : C.S.I Centre, 5, Whites Road,
Royapettah, Madras - 14.**

Jointly organised by :

CHRISTIAN CONFERENCE OF ASIA (CCA)

AND

CSI COUNCIL FOR HEALING MINISTRY (CSI CHM)

WHOLISTIC APPROACH TO THE
DIFFERENTLY ABLED
ON
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CHRISTIAN COUNCIL OF INDIA (CCI)
FOR THE PEOPLE OF INDIA
AND
FOR THE PEOPLE OF THE WORLD

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PREFACE

During the recent past there have been many instances where I was confronted with a very basic question and that raised in Church forums, as to what really is meant by 'Christian Response'? The issue has come up as the local church tries to understand its role in 'mission' in the context of emerging challenges in contemporary society. The curiosity and the spirit of enquiry behind it is very genuine. Is there a dividing line between a 'secular response' and a 'Christian response' when you are handling a human problem? There are many expressions that we employ habitually and unthinkingly. They often serve as labels without becoming the 'control boxes' of our thinking or responding. 'Christian response' stands in danger of becoming one such turn of speech. So it is helpful to consider as to what we mean by this expression.

First let us state the obvious. The very fact that we all talk about a 'Christian response' at all, indicates that it is different from other responses. But the very ethos of our times is sceptical and uneasy about what is unique. So there is a likelihood that even as we talk about a Christian response we may be under pressure to by-pass what is unique about it. Jesus said that the Kingdom of God was like a hidden treasure (Matt. 13:44). Christian perspective is the one from which this hidden treasure becomes 'visible'. The most basic thing about the Christian response is that it helps unveil what is otherwise 'invisible'. A good example of this is found in John 8, in the instance of the woman taken in adultery. When others looked at the situation they saw only a sinful woman. Jesus insisted on the visibility of her hidden exploiters. They had to be seen as part of the total picture, only because of a purpose that was 'hidden' to the rest. That purpose was the reformation and the spiritual rehabilitation of the woman. So let us say this Christian response is one that works out all its details in terms of Godly purpose. It is not just people, it is the purpose that makes a response 'Christian'. Suffering does not become Christian because the person suffering happens to have a Christian name. It becomes

Christian when it is endured for the sake of the Lord (Matt. 5:11). A Christian response hence, results in inputs that are unique. As a faith community, we are required to bring the discipline, resources and goals of our faith to bear on what we are engaged in doing. No situation is in itself Christian. We have to 'Christianize' the given situation. That is what our partnership in the 'mission' of Christ is all about. When it is attempted, we begin to see needs, resources and tasks to which the world is blind. 'My ways are not your ways' says the Lord.

The CSI and its Council for Healing Ministry have been engaged in efforts to equip the local congregations to become transformed as agents of healing. In our effort to rediscover that mission, we have become conscious of the many challenges, both existing and emerging, that calls for a Christian response. It was in this context that the challenge of disability was identified as an area of concern to be prioritised by the local congregations.

From the secular and utilitarian perspective, the disabled or the differently-abled may seem mere objects of pity. That was how it was prior to the ministry of our Lord. They were characterised by helplessness and social neglect. In the old testament there is a tragic instance of a Prince-Royal who was maimed through a childhood accident (II Sam. 9:8). His sense of self worth was so low that he referred to himself as a 'dead dog'. According to the Hebrew tradition and its laws, 'disabled' animals could not be offered in sacrifice. They have to be certified as 'blemishless' to be acceptable for sacrificial purposes. Perhaps Jesus was also reacting against this 'bias' when he said, 'I desire mercy, not sacrifice'. He confronted the doctors of the law with the assertion in the case of the man born blind (John 9) that his disability was not on account of his sins or the sins of his parents. Jesus went on to introduce the challenging thought that disability afforded opportunity to exemplify the glory, goodness and greatness of God! That indeed is the essence of a Christian response.

The National Consultation on 'Wholistic Approach to the Differently Abled' proved to be a major landmark in the life

and witness of the CSI Council for Healing Ministry. The participants in the Consultation were a select group from main line churches and organisations in India involved in programmes for the differently abled. We hope and pray that this National Consultation will now serve as a trend setter in overall policy planning. We are indeed grateful to the Christian Conference of Asia and particularly to its Secretary Mr. Prawate Khid-arn, for entrusting the CSI Council with the responsibility for holding this major National Consultation and co-funding the project. We had a galaxy of eminent personalities serving as resource persons, each of whom is a well known authority in the respective field. On behalf of the Council, I express my sincere gratitude to all of them.

I should express my sincere thanks to Dr. M.C. Mathew, Director, ASHIRVAD, Madras, for helping us from the initial planning on. We are indebted to him on many counts not only for the wealth of experiences, which we could draw upon, but also for being with us throughout, sparing his time and energy and tending to even the minutiae.

I am grateful to the Officers of the Synod for their encouragement and support, particularly for making available the required funds. My thanks are due to Bishop G. Christdhas, Chairman of the Council for his unstinted support and co-operation.

I take this opportunity to express our sincere thanks to Mr. T.S. Menon, Principal, (Rtd.) Ravi Varma School of Painting, Kerala, for helping us in organising an exhibition as part of the Consultation. The portrait gallery of eminent personalities who were differently-abled was his exclusive contribution. We are grateful to the Directors of TRCR, Madanapalle and Government Institute for Rehabilitative Medicine, Madras, for exhibiting a wide range of innovative prosthetic and orthotic appliances.

I would like to especially thank Ms. Tina Susan George, (Co-ordinator, Special Projects, Communication) for her invaluable contributions in assisting with the Conference Planning and also

taking on the responsibility of publishing the Consultation proceedings.

We expect this document to be a tool in our 'Christian response' and thus stimulate and evolve a new understanding in our approach to the differently abled.

Dr. George Joseph

PROGRAMME

27.11.1995 (Monday)

9.00 — 11.00 a.m. — Inauguration

11.00 — 11.30 a.m. — Tea Break

11.30 — 1.00 p.m. — Introduction of the Core-theme
'Understanding the differently abled
from a christian perspective'
PROF. GEORGE KOSHY

'Church's response to the differently
abled'—Equipping the local congrega-
tion in mission
DR. GEORGE JOSEPH

Chairperson:

RT. REV. DR. D. POTHIRAJULU

1.00 — 2.30 p.m. — Lunch Break

2.30 — 3.15 p.m. — Kingdom of God and the differently
abled

RT. REV. DR. D. POTHIRAJULU

3.15 — 3.30 p.m. — Tea Break

3.30 — 5.00 p.m. — Community based Rehabilitation

DR. S. HARIHARAN

DR. J.C. VIJAYAN

Chairperson :

DR. M. THANGAVELU

5.00 — 6.00 p.m. — 'Inter-disciplinary approach to
Rehabilitation'

DR. SURANJAN BHATTACHARJEE

Chairperson :

DR. C. RAVINDRANATH

6.00 — 8.30 p.m. — Informal session.

28.11.95 (Tuesday)

- 8.30 — 9.00 a.m. — Devotion : PROF. P. ZACHARIAH
- 9.00 — 9.30 a.m. — Reflections on the previous day's proceedings
DR. M.C. MATHEW
- 9.30 — 11.15 a.m. — 'Areas of unmet needs'
PROF. P. ZACHARIAH
'Learning from what they are'
DR. M.C. MATHEW
Chairperson : MS. CLAIRE HEATON
- 11.15 — 11.30 — Tea Break
- 11.30 — 1.00 p.m. — Panel Discussion — 'SPECIAL NEEDS'
Moderator : DR. S.G. CHURCHIN BEN
Panelists:
SR. DR. RITA MARY
(on hearing impairment)
BR. DEVASY MADAVANA
(on visual impairment)
MS. CLAIRE HEATON
(on physical handicap)
MR. A. JEYABALAN
(on institutional care for the differently abled)
- 1.00 — 2.30 p.m. — Lunch Break
- 2.30 — 3.15 p.m. — Integrating Rehabilitation in primary health care
DR. S.G. CHURCHIN BEN
Chairperson : DR. CHINOY CHACKO
- 3.15 — 5.30 p.m. — Tea Break

- 3.30 — 5.30 p.m. — A closer look at care models
Chairperson :
PROF. A.J. SELVAPANDIAN
Family based learning and therapy
MR. Y. SIMPSON
- Vocational preparation of the
differently abled
DR. M.V. THOMAS
- Rehabilitation—Organisational aspects
and potentials in networking
MRS. ALOKA GUHA
- 5.30 — 8.30 p.m. — Dinner Break
- 8.30 — 9.15 p.m. — Video Shows

29.11.1995 (Wednesday)

- 8.30 — 9.00 p.m. — Devotion : FR. JOE MANNATH
- 9.00 — 9.15 p.m. — Reflections on the previous day's
proceedings
DR. M.C. MATHEW
- 9.15 — 11.15 a.m. — Education and training of the
differently abled
PROF. P. JAYACHANDRAN
Ethical issues in rehabilitation
FR. THOMAS P. KALAM
Chairperson : DR. GEORGE JOSEPH
- 11.15 — 11.30 a.m. — Tea Break
- 11.30 — 1.00 p.m. — Issues of Justice in Rehabilitation
FR. R. CUTINHA
Perspectives on Integrated Rehabili-
tation—with focus on the leprosy
afflicted.
DR. G.M. JEYABALAN
Chairperson : PROF. D. YESUDHAS

- 1.00 — 2.30 p.m. — Lunch Break
- 2.30 — 3.15 p.m. — The way we view those who are
different from us
DR. M.C. MATHEW
'Brainstorm session'
(topics for group discussion
preparation of interest groups)
- 3.30 — 5.45 p.m. — Discussion in 4 groups on the decided
topics.
- 6.30 — 8.00 p.m. — Cultural programme
- 8.00 p.m. — Dinner

30.11.1995 (Thursday)

- 8.30 — 9.00 a.m. — Devotion : REV. J.D. SOLOMON
- 9.00 — 9.30 a.m. — Reflection on the previous day's
proceedings
DR. M.C. MATHEW
- 9.30 — 10.15 a.m. — Emerging perspectives in community
based rehabilitation
MRS. CHRISTIE ABRAHAM
- 10.15 — 10.30 a.m. — Tea Break
- 10.30 — 1.00 p.m. — Broader Issues in Health and
Rehabilitation
DR. C.M. FRANCIS
- 1.00 — 1.30 p.m. — Concluding session
- 1.30 — 2.00 p.m. — Holy communion
- 2.00 p.m. — Lunch

1.12.1991 (Friday)

- Trip to Mahabalipuram

UNDERSTANDING THE DIFFERENTLY ABLED FROM A CHRISTIAN PERSPECTIVE

PROF. GEORGE KOSHY*

You may be wondering, as I am wondering myself, why I have been asked to talk about 'Understanding the differently abled from a christian perspective', because this is a very theological topic. The only reason I can think about, for Dr. George Joseph asking me to speak about this subject is, that I am 'theologically handicapped', being a layman with no theological training at all!

Before we try to understand the problem of the disabled from a christian perspective, we should look at the problem itself, to a certain extent. Care for the handicapped is an enormous problem in our country. The total population of the differently abled in India, is about 15 million, I am told. Of this, those with orthopaedic handicap is about 5.4 million, visual impairment about 3.4 million, hearing impairment about 2.75 million, intellectual disability 0.6 million, and leprosy afflicted about 3.2 million. That is the enormity of the problem. It is obvious that the government cannot tackle this problem alone. In fact, the government cannot do much in providing care for people who are differently abled in many ways.

In the first three 5 year plans, the government help came in the form of grant to voluntary organisations which are engaged in running rehabilitation centres. During the next three 5 year plans the policy was much the same, but the grants were much smaller. By the time we come to the seventh five-year plan we see the emphasis of the government changing, from institutional care of the handicapped to non-institutional services like education, service, training, distribution of credits, prevention programmes etc. The sixth five-year plan said, 'The major emphasis will thus be on social development than on

* General Secretary, The Church of South India, Synod.

social welfare', not giving grants to centres of rehabilitation, but investing money on the differently abled, which will help them to develop themselves. The seventh five year plan document also said 'The main thrust in the programme for the welfare of the handicapped will be on prevention of disability' and the plan refers to strengthening of health and nutrition as well as accident prevention, immunisation against a host of communicable diseases, prevention of nutritional anaemia, blindness due to Vitamin A deficiency etc. The government is very conscious of the fact that the co-operation of voluntary agencies or non-governmental agencies is essential in meeting this challenge. The Ministry of Welfare has declared, 'Non-governmental organisations and social groups will continue to play a significant and predominant role in the welfare of the handicapped, in consonance with India's domestic framework'. As a matter of fact, the government wants to encourage private agencies and non-governmental organisations in their efforts of alleviating the suffering of the differently abled.

This is where we come in. We are given this great opportunity and responsibility to respond to this great human need. The church has always maintained that mission does not only mean proclamation of the gospel, but also responding to human needs.

To understand the problem of the differently abled from a christian perspective, we must look at Jesus Christ himself, and try to see what Jesus did to them. In the passage in St. Luke's Gospel which is usually known as the Manifesto of Jesus Christ (Luke 4:18-19) it says 'The spirit of the Lord is upon me, because He has anointed me to bring good news to the poor, He has sent me to proclaim release to the captives, recovery of sight to the blind, and let the oppressed go free.' Jesus saw his Mission as liberating people from bondages, from handicaps, restoring the disabled and the sick to their full humanity. There is another passage, John 10:10 where Jesus says 'I came so that they may have life, and have it abundantly'. Jesus Christ is offering life in all its abundance,

and we are engaged in the mission of giving people this abundant life.

At the time of Jesus, the disabled people were considered as outcasts, unclean, sinners. The jews believed that all diseases were caused by sin—either the sin of the person concerned, or the sin of his parents. Remember the blind man about whom the people asked, ‘why is he blind, because he sinned or his parents?’ The jews believed that when the child is in the womb of the mother, if the mother commits a sin, it affects the child also. Every disease was supposed to be the result of sin. We don’t believe that now. But in Jesus’s time, lepers and the handicapped were outcasts in society.

In healing these people, Jesus Christ was doing a very revolutionary thing. Or, He healed them in a revolutionary manner. In many instances in the Bible, we read that Jesus touched the patient—the leper, the blind man etc. Touching a leper, or touching an outcaste, was also a sin for a jew. A jew would not do that - a Rabbi would never come anywhere near a leper or the handicapped. Jesus was going to Jerusalem, from Jericho and this blind man was shouting for help. Those who were following Jesus asked him to shut up, ‘Don’t come anywhere near’. But Jesus asks him to come near him. Jesus was doing a very revolutionary thing when He was healing these people.

Another significant point about these healing miracles is that Jesus very often healed these people on a Sabbath. Something, again, which a Jew would never do. The man with the paralysed hand, the woman bent for 18 years, the paralysed man at Bethesda for 38 years, the blind man in John’s gospel—all of them are healed on a Sabbath. This was because Jesus believed that man was more important than Sabbath. A theologian has said that the most revolutionary statement Jesus Christ has made is that ‘Sabbath was made for man and not man for the Sabbath’. Jesus was prepared to violate the rules about Sabbath to restore the dignity of a human being.

Usually we think of these instances of healing as ‘miracles’—miracles which reveal the power of Jesus. But if you go

deeper into what Jesus did, we find greater significance in these acts of healing.

First of all, what Jesus was doing, was an expression of his solidarity with the marginalised, the poor, the disabled. They were considered by the society as outcasts. By healing them, He was bringing them into the mainstream of life. He was bringing into the mainstream of society those who had been kept outside the society. He was restoring these people to their full dignity as human beings. He was giving them abundance of life, for which he came.

Secondly, Jesus was empowering the powerless by healing these people. Jesus's actions were aimed at empowering these powerless people. This was a threat to those who were in power. Empowering the powerless is always a threat to those who are in power. The gospel liberates people from their handicaps and bondages and helps them to assert their rights and privileges.

The third point we note in Jesus's healing ministry is that caring for the handicapped was a costly affair for Jesus. We may see he was very powerful and so he could easily heal these people. But, it was a costly affair, because the Pharisees were provoked into conspiring to kill him because he was helping these people. In standing in solidarity with the poor and the marginalised, Jesus had to ultimately lay down his life for them.

When we look at the mission of Jesus Christ in this light we shall be able to do our work diligently for the differently abled. Our mission for those with disability, therefore, takes its cue from what Jesus did. In our work among the differently abled, we must always remember that they need, not sympathy, but acceptance.

This fact has been widely recognised now. The change from the word 'disabled' to 'differently abled' is a recognition of this. It is well-known that those who suffer from impairment of one faculty or other, develop other faculties. So the term 'differently abled' refers to the enormous potential that remains

hidden and untapped in such people. History is full of examples of men and women who have overcome their handicap. As a student of English Literature, I always remember Milton. Milton the great English poet was visually impaired. It is after he lost his sight that he wrote the great epic 'Paradise Lost'. When he lost his sight, he developed other faculties. It is said that very often in the middle of the night, suddenly he would get up, highly inspired, call his daughter and dictate poetry to her. It is also said that Milton had a marvellous vocabulary. Eventhough he was visually not well, he could remember many words. Apparently he has used more words than any other writer in the English language, except Shakespeare. Shakespeare they say used about 12,000 words in all his plays; Milton used about 9,000 words. You and I manage with around 2000 words. Napoleon, Roosevelt, Helen Keller, etc. are other great people who were successful in overcoming their impairment.

When I was a student in Madras Christian College, I had a friend called Joseph, who was visually impaired. He was doing his M.A. in History. We used to read to him, in turns. He passed his M.A. with distinction. I met him 20 years later. I went to him and spoke to him. Immediately he recognised me and remembered my name, from my voice. A classic example of how you develop some faculties when you lose another faculty.

The differently abled need acceptance in society, not sympathy. In CSI, we have some hostels called integrated hostels. They are called so, because in those hostels differently abled children live together with normal children and it is hoped that by doing this they will not feel discriminated against or isolated from the rest of the community. It is also good for the so-called normal children to have the differently abled children among them.

It is also very important to find good jobs for the differently abled people. Disabled people have historically been objects of pity, sympathy, objects of our social service and beneficiaries of charity. What they need is a suitable job which

will give them dignity and independence. Recently I read an article in a magazine of the Church of Scotland about an industrial chaplain in the Church of Scotland who is a handicapped person. When a child, he was a victim of polio and so has difficulty with one arm and one leg. After passing school education with good marks he wanted to go to the university for further studies. But the people told him, no, no, a handicapped person like you must find a good job. That is better than studying. And they fixed up interviews for him with a bank and an insurance broker. When he went to the Bank for his interview. The interviewer showed great sympathy for him. He said 'you will have to count coins, sometimes you will have to carry big bags of coins, so you will find the job very difficult'. Sympathy. But no jobs. About that experience, the chaplain says 'I was too young and too stunned to argue. I was devastated and I cried all night. And I didn't want to go for the other interviews'. But he was persuaded by his friends to go. And at the second interview, he got the job. Then he said: 'I was elated....over the moon. I was a man, I had a job..... I have never forgotten those two days, especially the liberated importance of having a job'. Apart from the income, work provides a sense of identity, self-esteem and the opportunity for dignified social conduct. For a person with disability, this is very important. Later on, this young man rejected by a Banker became an ordained presbyter, and at the moment he is leading a campaign against the discrimination of the disabled in the job market. He is also working for equal pay for the differently abled.

Finally, above all, we must be able to give hope to the differently abled people. There are two categories of differently abled, I believe. One, those who bemoan their lot and feel helpless and desperate. The other is a group who with faith and courage overcome the handicap and develop their faculties to lead an independent and useful life. Our task is to enable those with disabilities to be in the second category—to give them encouragement and faith. This is a spiritual task. The differently abled people need not only physical treatment and adjustment, but also emotional and spiritual support; and with this, the abundant life that Jesus Christ promised.

CHURCH'S RESPONSE TO THE DIFFERENTLY ABLED

-Equipping the local congregation in Mission

DR. GEORGE JOSEPH*

It might come as a surprise to at least some of us that the first ever healing miracle that happened in the early Church is in the context of the differently abled. The reference here is to the familiar story of healing of the lame man at the temple gate.

Let us take a closer look at what happened on that day. The characters in the incident could easily be clubbed into three: the lame man who is the principal character, Peter and John, and finally the usual crowd. To put it in contemporary terms, the characters include a 'person, differently abled', a couple of 'potential care givers', and thirdly, the 'community'.

The lame man is 'placed' outside the temple gate. Being a 'congenital cripple,' he certainly could not have reached there by himself. Some kind-hearted among the community took pity on him and decided to find him a means of livelihood. They chose to place him in front of the temple so that he could seek alms. The God-fearing people who came to the temple everyday would throw a dime, many considering it an act of kindness on their part—a familiar scene even today in front of our churches every Sunday. Bringing the cripple daily to the temple gates and his maintenance by alms is the perfect example of community life lived at a 'compromise-level'. This is certainly not very demanding and would well go as an overt act of charity as is commonly understood.

The lame man didn't expect much from Peter and John. They must have passed the same way many times earlier. For the lame man, this would have been a very familiar sight. For Peter and John, the lame man's plea had never evoked any response. But on that day, it proved to be different.

**Executive Director, CSI Council for Healing Ministry*

Peter and John halted to consider his plea.

If you carefully follow the story, for the lame man, initially, it was a 'denial' ('silver and gold have I none') followed by the 'acceptance'. For Peter and John, it certainly was a critical moment—it was a moment when they remembered the Lord's promise, that the disciples would do 'greater things' when He had gone to the Father and the Spirit had come to them (John 14:12). And so they pronounced, 'In the name of Jesus Christ of Nazareth, stand up and walk'.

The pinnacle of the miracle comes when the lame man, cured and restored to normalcy, as a sign of his complete restoration leaps with joy and enters the temple. In all probability it was the ultimate fulfillment of the deepest desire in his heart.

There are many lessons to be learnt from the story of the cured cripple. It vividly represents the reality of our own times. Let us boldly admit that we carry the lame man to the temple gate and leave him there.

What has been the Church's response to the differently abled ? The Church has always been in the fore-front in caring for the disabled. However, a closer look at the care models that we have evolved would reveal that these have stemmed more out of 'pity' than of compassion ! It is worth taking note that the term 'compassion' is so different from 'pity'. 'Compassion' reveals a deep feeling for, and an understanding of suffering—a spiritual consciousness of the personal tragedy of another, a selfless tenderness as well as the capacity of sharing the feelings of another. This is the model that our Lord has left before us. Jesus had 'compassion' on the crowd. The gospel is replete with examples of how he responded to the needs of people—the blind, the deaf, mute, the cripple, the epileptic, the paralytic, and also those closely associated with them. 'And He healed them all'. (Matt. 4.24).

The challenge before the Church is to examine whether the care models that we have accepted and perpetuated, really reflect 'compassion' and the willingness to share the pain and

suffering of the differently abled. Do they still continue to be objects that evoke in us the feeling of 'pity'?

The undergirding philosophy that ought to guide the care programmes adopted by the Church is that Jesus identified Himself with the suffering. The pen-portrait of Jesus reveals, '....he hath no form nor comeliness, and when we shall see him, there is no beauty that we should desire him. He is despised and rejected of men; a man of sorrows, and acquainted with grief; and we hid as it were our faces from him; he was despised, and we esteemed him not.' (Isaiah 53:2-3)

Do we perceive this portrait of our Lord in those who are different from us and are, therefore, suffering ? Michael Mayne, Dean of Westminster says that according to one of his close friends, the crucified Jesus is the only accurate picture of God the world has ever seen. Dietrich Bonhoeffer wrote from the Nazi concentration camp 'only a suffering God can help'.

It is most important that in the context of the differently abled, the Church remains in solidarity with those in pain and suffering. It is at root, a giving of yourself to another, come what may. Love costs us dear. It demands loyalty and sacrifice. What the cross of Christ shows us is that our pain and anguish are known intimately to God Himself. The presence of Jesus once in history is the presence of God as He has always been and always will be.

What did that love cost Peter and John as they shared the pain and suffering of the lame man? They were arrested and imprisoned for their expression of compassion and love—for freeing the lame man from captivity.

What did the Church gain ? '....the number of believers now reached a new high of about 5000 men'! (Acts 4:4).

Jesus said, 'I have come that they may have life, and have it to the full' (John 10:10). What does it mean to us? —a life of success? a life of comfort ? a life of pleasure or a life free of pain? Far from it. The 'fullness' that we aim,

is achieved in *Growing Through Pain*. To be 'fully alive' means to be like Jesus Himself. One needs to be as open as possible to life's experiences. Jesus was able to bear the whole range of human feelings. He knew ecstasy and joy, He knew ridicule and humiliation. He was angry, He wept. He was lonely, He knew fear and anxiety. He was bereaved and tortured. None of these He avoided. He had the courage to meet them. This ability stemmed from his unity with God (John 17:21).

He affirmed that this unity was God's intention for all people in all ages. It is certainly not an escape from the consequences of living in relationship with others, especially those who are disabled—the differently abled. One has to accept them for what they are.

In India, we are referring to 80 million people—that is, 10% of the population who are known to be differently abled. It is estimated that one out of every 10 people is disabled. Another 40% constitutes their families who are affected economically, socially and emotionally. We also know that much of this occurs from preventable causes that are known to us and could thus have been averted.

What is the congregations' role in the light of these possibilities? First and foremost, there is a need for creating an understanding and awareness about the extent and magnitude of the problem. In India, in spite of the National Blindness Prevention Programme, 20-30,000 children lose their eyesight due to vitamin A deficiency, and in spite of the Universal Immunisation Programme, there are still epidemic outbreaks of polio! The impact of government-initiated programmes is notional, especially in rurally based communities. Equipping local congregations in mission therefore becomes a priority. The guidelines for the mission are clearly outlined in the 'Nazareth manifesto', where preaching and action alternately take dominance—one follows the other (Luke 4.18).

Let me also refer to another scriptural compulsion about the congregational role. Refer to Ezekiel 33:6,7. It mentions the watchman's role given to the congregation, to warn the

people. In our own context, it may be creating awareness among a rural community about available options, ways and means of avoiding tragedies and certainly the choice between life and death.

Once the nature and extent of the problem is identified, surely a positive response needs to be evoked. This would involve resource mobilisation-material and human. It is important that the family plays a vital role—so also the neighbours, friends, etc. There is a need to identify volunteers in a given setting who could be trained for specific tasks.

In this, the local congregation is only accepting the role model set before us by our Lord. In essence this would reflect:

‘Love of our neighbour in all its fullness simply means being able to say to him, ‘What are you going through?’



‘KINGDOM OF GOD AND THE DIFFERENTLY ABLED’

RT. REV. DR. D. POTHIRAJULU*

I would like to begin with an input from developmental psychology because I believe that our concern today bears a great deal on human development. You would agree with me that human development is not limited to physical development alone but it embraces psychological, moral and ethical dimensions of development as well, which need to come under the over-all spiritual development.

Let us turn to the world of children where development is at the initial stage.

‘All that tastes sweet are good’; ‘All that looks pleasing to the eyes are good’ and ‘All that smells pleasant are good’ are but a few statements that you can expect to originate from children. If such an attitude is found with adults we would call it childish, as compared to childlike. Psychologists help us to understand that there are stages of development in ethical and moral behaviour and that perspectives change as people grow. For example what do we think about a child who says ‘what tastes sweet must be good’? Obviously a little child is not able to see the other implications or dimensions of the effects of the food that tastes sweet or the effects of sugar for that matter. As an adult one could say ‘even that which tastes bitter can be good and good for health’. After years of struggle and awareness building, we now come across people who convincingly take a different stand and proclaim ‘black is good’, ‘small is good’ and so on. A new perspective has been gained, a new set of values achieved and a new ethos has come into being.

As Christians we believe that the Kingdom of God has been proclaimed. New perspectives and human values that

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have come in, belong to the realm of the Kingdom. Our Faith is that God in Jesus has redeemed the whole humanity from its brokenness and has reconciled it to Himself. The Gospel of Jesus Christ brings to us, 'newness in life.' In the Book of Revelation, God says, 'Behold I make all things new'. The Bible talks about the new wine, the new heaven and the new earth. The promise of the Bible is that old things have passed away and all things have become new. Jesus himself is presented as the new Adam. The old Adam brought sin and death. The new Adam brings new life to the whole humanity.

The society into which Jesus came was more a legalistic society than a redeeming community. It had a legalistic perspective rather than a perspective of transformation, a higher level of growth or moral behaviour in human development. As you know, in the olden days leprosy patients were branded as 'lepers', were put into a dehumanised category, considered to be outside the grace of God and put away from society, thus causing a rift, as it were, in society. Take the case of the woman caught in adultery. The people wanted her to be stoned to death. There was no reference to the man who was also a party to it. Apart from discrimination, the crucial question is whether there was any room for restoration.

We will take one more example to see how redemption is possible with change in perspectives and how Jesus helped people in this process. In the society into which Jesus came, a man born blind stood condemned as the effect of the sin of the parents which, the society believed, was the cause of his blindness. There was no dignity attached to his very existence. The deaf and the dumb were to be seen as 'possessed' and not as 'persons'. We now have to ask ourselves, 'Is the Indian society with its strong accent on karma and fate, any different from the society that Jesus witnessed'?

It is into such a society that Jesus brings the good news of the redeeming love of God. Jesus touched and healed the leprosy patients and commended them to religious leaders to be treated as normal persons worthy of the Kingdom of God. We can say that a humanisation process was set in motion.

The Church is called to carry on this Mission of the process of humanisation. Jesus restored the woman caught in adultery and delivered her from condemnation. A new opportunity was given to her. It was the beginning of a process of new life in her. The Church is called to carry on this Mission of Restoration and Transformation. Jesus listened to the cry of the man born blind. He took compassion on him. He recognised him as one belonging to the generation of the faithful. The human dignity of the man born blind was upheld. The Church is called to carry on the Mission of bringing dignity to people at all levels and in all situations, thereby bringing them into the promises of the Kingdom. Jesus healed the deaf and the dumb. He did not scorn at them as devil-possessed. He communicated with them and enabled them to communicate with others and relate themselves as people to people. Their 'personhood' was upheld. The Church is called to participate in such a Mission of God upholding personhood.

These are but a few examples in the Ministry of Jesus where you find the social orders challenged, religious beliefs questioned, new relationships built and the way for a new social order opened. In short, the Kingdom of God was proclaimed and new perspectives gained.

For our purposes, let us analyse the examples further to identify, with whom should the new perspectives be found?.. with the so called 'able' or with the so called 'disabled'? Certainly with both! Both categories of people are in need of salvation!! We know very well that the blind, the lame, the leprosy patient, the deaf all contributed to the old social order. The old society considered themselves as condemned, bearing the sin of the forefathers. They felt excommunicated from the religio-social fabric, and in their hearts they condemned themselves. 'Son of David, have mercy on me'. There was total frustration in the mind of the man lying at the Pool of Bethesda who lamented that there was no one to take him to the Pool of Healing. The perspective that these people had inherited was that they were totally 'disabled'.

A few days back I was watching a B.B.C. news broadcast on T.V. It talked about a war situation. It showed a picture of powerful weapons and ammunitions bursting into a ball of flames and a cloud of smoke and the entire mass of potential being shattered into pieces. The news reader said, 'the ammunition were either destroyed or disabled'! This points to the most cruel attitude found in the popular notion where 'disabled' is equivalent to being destroyed, useless, disorderly and dead. Perhaps both the 'able' and the 'disabled' contribute to the propagation of the notion. Therefore it is important that both the categories of people, the enabler and the enabled gain the right perspective. A transformation of mind is needed to affirm that the people in need are people with a lot of potential and therefore they are to be seen as the 'otherwise able' rather than 'disabled'.

I have worked in villages as a rural pastor and I have found the polio affected children crawling in the mud—dirty and uncared for. The worst thing is that the parents consider such children as a burden and a curse. I don't have to say what happens to the cerebral palsy affected children or those with slow intellectual growth. Perhaps they are treated in a subhuman manner. And they are seen as a cause for irritation at home often battered and abused by the parents themselves.

I should say that we the so called 'able' are the real disabled, lacking in skills of communicating and relating to the otherwise able. Therefore, real transformation is needed for both categories to look at themselves as people, as persons, as loving and lovable children of God, bringing joy to each other and always enjoying healthy relationships, the absence of which is pain and suffering.

Once I visited a home for children with intellectual needs and the teachers of the school said these children bring great joy to them as they are a happy lot and are most affectionate. On another occasion I was talking to a few trainees working with children affected with cerebral palsy. They shared their experiences with me. They said initially they had a lot of prejudices against these children. They didn't want to touch

them because these children dirty themselves and so they always tried to escape from the situation. But, within a short while things changed and they began to love these children, hug them and look at them as God's children. What a transformation of attitude and change of perspective to the whole situation!

I have not myself worked among the 'otherwise able', but I have listened to the skilled workers who minister to these children. For me they are the modern evangelists who carry the good news of healing, to those who need it.

I also know of whole local communities, people of all religions and of different occupations, who are involved together in the ministry to the 'otherwise able'. Kodaikanal circle of friends is a typical example. Since this ministry brings together people irrespective of caste, class or creed, a sense of unity emerges as people come together in restructuring their own societies and seeing meaning in their own lives.

I would like to summarise my thoughts by affirming that the differently abled are treasure houses with rich potential. They are able to find meaning in their own lives and bring meaning into the lives of others as well. They help us to undergo a transformation of attitudes, gain newer perspectives on pain and suffering, grow into a new spiritual experience of upholding the human dignity of our neighbours, preach the Kingdom of God and establish peace and justice in the world.



COMMUNITY-BASED DISABILITY PREVENTION AND REHABILITATION OF PEOPLE WITH DISABILITIES

DR. S. HARIHARAN*

People with disabilities constitute an alarmingly high percentage of the population in our country where low per capita income makes comprehensive disability prevention and rehabilitation services a prohibitive proposition. Hitherto, we have been increasing these services with the help of international donors and with assistance from developed countries.

A number of large surveys in industrialised countries have indicated the prevalence of disability to be about 10% of the population. In developing countries, hundreds of similar studies have been made. It is difficult to compare the result of the various studies because of the variety of methods used. But it appears reasonable to conclude that 7-10% of the population in developing countries are people with disabilities. This figure is less than the estimate for industrialised countries.

The incidence of some disabilities is higher in developing countries than in the industrialised ones. However, in developing countries people with disabilities have a shorter life span. The most important factors which contribute to the death of the person are infectious diseases and diarrhoea. In some areas most children who are born with a disability or acquire one in early life, do not survive beyond the age of 20 years. Similarly elderly people with disabilities do not live long after the onset of the disability. As a consequence the prevalence of disability in developing countries is lower than in the industrialised countries.

As our health services improve, survival rates also increase. Although the incidence of disability can be expected to decrease, the prevalence will go up. When infant and child mortality

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rates diminish and the proportion of elderly people in the population increases, we can expect the prevalence of disability to be around 10%.

On the basis of field experience it is estimated that 100-125 million people with disabilities in developing countries (or 2.5-3% of the population) could benefit from rehabilitation efforts. The number is definitely increasing. By the year 2000 A.D we should expect around 130-150 million people to be in this group.

Another important observation is the inequality in accessibility of services for people with different types of disabilities. In our set-ups, we have a few difficult questions. Do our programmes make optimal use of the available resources, to reach the greatest number of disabled persons? Are the programmes implemented in the most economic of ways? Are the disabilities detected very early and treated adequately? Most often persons with minor impairments end up as being severely handicapped and totally dependent with permanent disabilities. This is primarily due to lack of proper attention.

It is estimated that at present not more than 2.3% of the people who could benefit from rehabilitation actually receive the service, i.e. only 2.3 million of the 100-200 million people who need services receive them.

Definitions:

The terms 'Disability' and 'Handicap' are used almost synonymously. Current concepts have thrown light into a 'Disability process' where the above terms can be considered as different.

The disability process may be understood by the following sequences.

'Causes' – Impairment → Disability → Handicap.

The components of this sequence are defined as follows:–

Impairments: any loss or abnormality in the anatomical structure or physiological or psychological function.

Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap is a disadvantage for a given individual resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is considered normal (depending on age, sex and social/cultural factors) for that individual.

Impairments and disabilities may be visible or invisible, temporary or permanent, progressive or regressive. Social and environmental factors can increase or decrease the severity of a handicapping condition.

‘Rehabilitation’ includes measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration.

‘Community Based Rehabilitation’ (CBR) involves measures taken at the community level to use and build on the resources of the community, for improving the condition of the impaired, disabled and handicapped persons, by involving the persons themselves, their families and the community in the programmes.

The concept of Community Based Rehabilitation (CBR)

CBR is a concept closely related to Primary Health Care (PHC). An integral part of the programme should be ensuring Health for All by 2000 AD

CBR has three fundamental features:

- (1) Focus on community involvement
- (2) Use of simplified rehabilitation technology
- (3) Service delivery systems.

None of these features are new, but the way in which they have been developed and combined to form a programme for rehabilitation, presents an unconventional approach.

The only reference in developing such CBR programmes is the WHO manual titled ‘Training in the Community for people with Disabilities’ (4th version 1989). This manual contains 34 modules comprising 4 guides and 30 training packages.

The four guides are

- (i) Guide for local supervisors
- (ii) Guide for Community Rehabilitation Committee.
- (iii) Guide for people with disabilities.
- (iv) Guide for school teachers.

The Training Packages are for family members of people with disabilities. There are training packages for seven types of disabilities—seeing difficulty, hearing and speaking difficulty, moving difficulty, feeling difficulty, strange behaviour, fits, and learning difficulty.

There are three categories of training packages

(i) *Information Packages* are meant to transfer knowledge about the disability to people with disability and particularly their family members.

(ii) *Prevention Packages* are used to prevent disabilities from turning chronic.

(iii) *Training Procedure Packages* are used to train family members in rehabilitation so that they can help the person with a disability to be more active.

Service delivery in CBR

Formulating technologies is not an end in itself. One has to think about people who would carry out the programme, train and supervise personnel and manage the programme. Rehabilitation tasks have to be distributed among different levels of service. This will require co-ordinated efforts by Ministries, Local, District, State and National level authorities and Non Governmental Organisations in the different sectors of rehabilitation. Community based services are not the same as community level services. A whole new system of services is required Coordinating efforts at the district, state and national

levels. What is important is to develop higher levels of service in response to community needs. If such services already exist, they may need to be reoriented.

The role of professionals

Professionals are essential at various levels of service. At the district level there needs to be an intermediate level supervisor or a CBR manager who can train the local supervisors, guide and supervise their work, manage referrals, maintain communication with all levels of service and manage the CBR programme at the district level. Such a person may not correspond exactly to any one current type of professional.

Constitution of personnel and proportion of needs met at each level of service in a community based rehabilitation programme

Level	Percentage of needs to be met	Personnel
National	10	Specialist doctors for all disabilities physical, occupational and speech therapists. Teachers for those with visual, hearing and intellectual needs. Teachers for vocational training, orthopaedic technicians and professionals for technological services.
State/ District	20	General or specialised doctors, some rehabilitation specialists. General Physicians, intermediate level supervisors, orthopaedic technicians, resource teachers, vocational trainers.
Community	70	local supervisors, community workers, school teachers.

At State and National levels, professionals will be involved in the delivery of complex rehabilitation services as well as in the training and supervision of personnel for district, state and national levels. It may be necessary to review the present curricula of various professional groups in order to prepare them better for the additional responsibilities they will have in a CBR Programme. It is also necessary to ensure that there are enough rehabilitation professionals to take care of referral services from the community and to provide appropriate management.

Approaches to Rehabilitation

To clarify the different approaches, the following operational terms are appropriate.

- (a) Institution based rehabilitation in bigger institutions.
- (b) Out-reach services through rehabilitation-camps, one day clinics, institutions in the community.
- (c) Community based rehabilitation (CBR) where resources are available in the community. Transfer of knowledge and community involvement, also called democratisation of rehabilitation.

Quality of life of people with disabilities

Mortality rates among people with disabilities are much greater than that among the non-disabled. There is often a lack of concern in society about environmental factors that cause or complicate disabilities.

People with disabilities often do not have access to community services and other opportunities available to normal citizens, such as health services, schools and educational institutions, skill training programmes, vocational training, job placements and so on.

The presence of a child with visible or stigmatising disability in a family may have negative consequences in the marriage not only of the child with a disability but also of brothers and sisters. Social segregation of people with

disabilities is extremely widespread. Negative attitudes and discriminatory behaviour towards people with disabilities are the 'rule' rather than the 'exception'. People with disabilities are often excluded from any position of leadership in the community. Most of them have no say in their own welfare and in policies and services aimed at them.

Conclusion:

The large gap between the services needed for people with disabilities and those provided, presents a dilemma. It is not possible to meet all their needs with services at the community level. However, upto about 70% of the needs could be met within the community. This would be a major improvement on the 23% of needs that are now being met in many situations. The remaining needs must be met through referrals in district, state, provincial and national levels, for which we already have good infrastructure. There should be adequate professional staff at those levels, to deal with problems that cannot be solved in the community.

We have ample evidence to stress that CBR is the answer to reach the disabled in our rural areas. Government of India has implemented the DRC Scheme (District Rehabilitation Centre Scheme) through the Social Welfare ministry as an important step in achieving CBR. With these we can hope that the goal of 'Rehabilitation For All (RFA) could easily be achieved by 2000 A.D.



COMMUNITY BASED REHABILITATION FOR PEOPLE WITH DISABILITIES

DR. J.C. VIJAYAN*

Introduction:

In discussing Community Based Rehabilitation (CBR) it is necessary to define disability, rehabilitation and community. Cultural and development factors influence the concept of disability to a great extent, in the developing countries.

People with disabilities:

The simple and early definition of a person with disability (P.W.D) was based on his/her difference in appearance and or behaviour. The perception of disability was thus oriented towards identifying those who were 'different' because of functional limitations and/or activity restrictions. In the industrial field people who were less productive – slow and lacking usable skills – were considered for disability benefits. Individual perceptions and restrictions in the environment also affect the process. The following operational definition by E. Helander could be used for some clarity.

A disabled person is one who in his/her society is regarded or officially recognised as such because of difference in appearance and/or behaviour, in combination with a functional limitation or an activity restriction.

Community:

The definition and understanding of the word community also differs in different parts of the World. The definition that was formulated by WHO in 1978 in relation to Alma Ata declaration is comprehensive:

A community consists of people living together in some form of social organisation and cohesion. Its members share, in varying degrees, political, economic, social and cultural

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characteristics, as well as interests and aspirations including health. Communities vary widely in size and socio-economic profile, ranging from clusters of isolated home steads to more organised villages, towns and city districts.

Rehabilitation:

The concept of rehabilitation has also undergone changes. The earliest ideas of charity and sympathy gave way to social justice of equal access to service and distribution of resources.

The need for considering rehabilitation as a human rights issue is imminent and is one of the cornerstones of the strategy of CBR.

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation.

Rehabilitation includes not only training of disabled people but also integration in the general systems of society, adaptation to environment and protection of human rights.

Protection of human rights is an obligation on the part of the authorities of each country, towards its communities and all citizens. Disabled people need to have the same rights to a life of dignity and there must be no exception. Special attention may be needed to ensure the following : access to health and social service ; educational and work opportunities; housing, transportation; information ; cultural and social life including sports and recreational facilities; representation and full political involvement in all matters of concern to them.

Disability Scenario

The World Health Organisation (WHO) estimates, that 10% of the world population are people with disabilities (revised estimates of Dr. Helander (1992) is 7.5%). It has been also estimated that 80% of these people are in the developing world. If we take into account the family members who also directly or indirectly get affected, the number would be anywhere between 20% to 25%

Studies have also shown that only 1.5% of the total population with disabilities receive the benefit of rehabilitation services. Maldistribution of available service facilities is a major problem in developing countries like India. Nearly 80% of people with disabilities are in the rural parts of India where less than 20% of the services are available. Almost all the disability care rehabilitation programmes are urban-based institutional services and most needy poor rural folk find it very hard to avail of such services.

Most of the disabilities are preventable when poverty, ignorance and poor environment are avoided. Malnutrition, infections and trauma are estimated to be responsible for about 50 percent of the disabilities. It is certainly disturbing that 50 percent of people with disabilities are children below the age of 15 years.

Evolution of Rehabilitation:

There is a felt need for programmes to take care of these people in their family settings. The rehabilitation services in the beginning was more of an expression of charity and sympathy. Institutions were established to provide basic needs (food, clothing and shelter) and thus charity homes became centers of rehabilitation. Later on certain other institutional services were established in urban areas, to provide education and vocational training. These programmes totally lacked participation of the family and many a time were seen as a way of getting rid of a person with disabilities from the family setting thus lessening the family burden.

In the last few decades there has been a shift in the methodology of services when institution based programmes were turned into community outreach programmes whereby services were taken to the people. These programmes were also very few in number and lacked proper follow-up and continuity of care. A welcome change that has come about in the field of Rehabilitation today is the effort towards making the programme of and by the people, with their full participation.

The charity services were thus replaced by people-oriented programmes for empowering people with disabilities and giving them equal opportunities for self-actualisation.

In the developed world with well-established programmes for prevention of disabilities, the methods of rehabilitation employed are quite comprehensive. There is emphasis on curative services and rehabilitation services to include medical and surgical intervention, physiotherapy, occupational therapy, provision of relevant aids and appliances to prevent impairment from progressing into a disability or handicap. Advancement in medical and related technology has considerably contributed to the overall development of mobility aids and appliances as well as modification of the environment to suit the needs of the disabled, thus helping them to cope with their personal and physical needs. The technological advancement has also helped people with visual and communication disabilities to take care of their own personal needs and at times even to grow in their academic life and job placement to a great extent. These services are available only to negligible number of people in the developing world.

Institution based programmes:

The institution based programmes in the field of rehabilitation services involve capital investment for buildings, special equipment and specially trained personnel. The increasing cost of care has been a great concern for health planners all through the years. These services became less and less person-oriented, more and more technology-oriented. Homes for the disabled established to meet their personal needs of education, medical rehabilitation etc., contributed to some extent and helped the families to ease their burden as mentioned earlier. These institutions have made many of the recipients of services dependent on the system of care thus losing the opportunity to integrate them in their own families, society and community. Special programmes started as day care centers to provide appropriate education, training and socialisation facilities for children also lacked the participation

of the family and the people. In certain larger institutions, special out patient facilities were introduced for training people with disabilities, providing counselling for the family, etc.

It was in this context that the newer approach of outreach from a large institution was envisaged. These programmes even when well organised, though served many people in need at a point in time, did not have provision for adequate care and follow-up. As a result many of the programmes of community outreach in the field of rehabilitation were not acceptable in terms of quality of care and follow-up service.

Community Based Rehabilitation

CBR is the newer approach promoted by the World Health Organisation (WHO) to reach unreached sections of people with disabilities. This can be considered to be a method very similar to the primary health care programmes, and is an alternative to the expensive, high technology institution-based rehabilitation programmes. Community Based Rehabilitation envisages utilisation of existing resources (manpower, local expertise) within the community to provide service and to promote integration of the people with disabilities into the society. CBR promotes home made technology to be used for making appropriate aids and appliances and utilisation of locally available materials for services. Awareness building and community organisation for community action to support people with disabilities is a main component of CBR. Rehabilitation programmes are implemented through trained village level workers from within the community, for better acceptability and functioning. Services are rendered to people in need in their own family context thus making the family a therapeutic caring home.

The Essential components of an ideal CBR programme could be the following:

1. It should be a programme organised, supported and monitored by the community.

2. Parents of people with disabilities and other community level workers from the community should be trained in caring for disabled persons.
3. There should be a coordinated effort for sharing of available resources in the community with the Government and Non-Governmental programmes. Such networking contributes towards cost effectiveness and self sustainability.
4. The community shall plan its own programmes based on availability of resources and experience of disability process within their own community.
5. It shall be a comprehensive programme for different kinds of disability providing kinds of rehabilitation services and support to people with disability.
6. An appropriate referral service system should be planned for specialised care currently not available.
7. Support to the psychological and social needs of the person with disability and the family should be a priority in approach.
8. Awareness building on matters concerning disability, such as preventive measures, 'acceptance' and provision of opportunities for the disabled should be a primary concern.
9. Ultimate goal of rehabilitation shall be total integration of the disabled persons in the community towards self-actualisation.

There has been many attempts in different parts of the world to realise the above objectives. The Government of India in 1985 initiated the District Rehabilitation Centre Scheme as a pilot project. This project envisaged a three tier service delivery system. A family level service integrated to the primary health centre and referrals in the district centre was the planned strategy. The evaluation done on this project by the Institute of Health management, Maharashtra in 1989 appreciated many

of the achievements but also pointed out many drawbacks including that of poor cost effectiveness. Many voluntary agencies later on started similar programmes with minor modifications in the methodology and some of them have been successful, thus making CBR a widely accepted phenomenon today.



INTER-DISCIPLINARY APPROACH TO REHABILITATION

DR. SURANJAN BHATTACHARJEE*

I have been asked to share with you our experiences on inter-disciplinary approach to rehabilitation at the CMC Hospital. There have been references made by earlier speakers to the Community-based rehabilitation approach. I acknowledge that there are no readymade answers and approaches, and that we only learn from each other. We do have different experiences and so I feel it is not essential to belittle each other's experiences but to keep learning from each other.

While I was mulling over this topic, I was watching cricket on television. Then it struck me that there are different kinds of games—those which you play by yourself, or those like tennis or badminton which you play in pairs. Then there are team-games like football or cricket. I am not certain if you will be able to decide which game is better or which is more fun. Different games have different advantages and disadvantages. The game that we choose to play is of our own choice and is often a response to a need that we have.

Similarly, inter-disciplinary work is not the only option, but certainly one of the options available and it seems to be appropriate to the institution I find myself in.

I often find that if I were to encapsulate the process of rehabilitation, I would call it an 'educative process'. The final product of our efforts should be to give hope to the differently abled people. We are educating people on how to cope with difficulties that cannot be wished away. If I were to look at the educative process through which children go, I would see that initially they have a primary school teacher who teaches them different skills, but as they go on to middle school or

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high school, different disciplines are taught by different teachers. There may be a Maths teacher, an English teacher or a History teacher. I know that society has developed these options because these different people with different expertise can try and give their perspective to the children. But as the child is being educated it is difficult to be certain which of these bits of knowledge is going to be most useful. We do not know when the child is in the middle school/high school, whether the child is going to be interested in geography or algebra, mathematics or the language.

But we expose the child to as much as possible so that the child has many options. So when ultimately the child is ready to choose, he knows what to choose from, because he has experienced them. I do not think my history teacher should feel disappointed that I took up science. Actually, the history I enjoyed in school has given me such a beautiful perspective to what I do. In fact, it is not the skill that a person uses that is as important as the process of empowerment, which actually gives the person options.

It is difficult to encapsulate rehabilitation. The various strategies used to face the problem are dependent on whether the person involved is a child or an adult, whether the person comes from a village or a town, whether the person has a mild handicap or a severe handicap. I think any attempt to generalise is fraught with problems because, then we tend to exclude individuals. Rehabilitation is about 'including,' about 'empowering.'

The multi-disciplinary team that is required to face the problem will again change from individual to individual—according to the person's circumstances and needs. My interest happens to be in persons with problems of the spinal cord. If I were to take a just born baby with a defect in the spinal cord, the team that would be needed may include a neurologist, a paediatrician, a plastic surgeon, etc., As the child completes one year, we may need a person from the orthopaedic department. As he grows, we might require special educators and therapists with various skills. At a later stage,

we require a vocational counsellor, a psychologist and so on. And therefore, it is very difficult to define the team that is required, unless one knows the context to which one is referring.

In principle, all that one can say is that the team needs to be identified according to the person's needs. Being able to provide the person with needs, as many options as possible, is our duty.

A lot has been written and discussed about the difference between a multi-disciplinary team and an inter-disciplinary team. What I understand to be the difference is that, in a multi-disciplinary approach to a problem, we have persons with various skills coming together and helping to solve a problem. However, they tend to remain within their own scheme of understanding, knowledge and application. In an inter-disciplinary team there is much more flexibility. Although people come from various backgrounds, they move towards the same goal and there is much more sharing and flexibility in terms of responding to a persons's needs. And, therefore, in terms of development, historically, most groups have moved from multi-disciplinary teams to inter-disciplinary teams in order to address a persons's needs more precisely.

This brief talk was an introduction to a 22-minute video film. The film is used at the CMC Hospital as a means to overcome the language barrier in communicating to persons from different regions, while carrying forward the educative process called rehabilitation. It is an introductory video used to tell people who come for help, what constitutes the process they are to undergo. Many people come to the hospital thinking that they would be given a medicine by which the 'problem' will go away. When they are told that it will not, they are shattered. It takes a fair amount of time to make them see that life would still go on, despite the disability being present. The film is the first step taken to educate the person about his/her disability and the kind of help he/she would receive.

28.11.'95

DEVOTION

PROF. P. ZACHARIAH*

Readings from the Scripture:

Joshua 3:14 - 17; 4:1-6; 4:21-24

In keeping with these scripture readings I would like to speak to you about 'journeys'.

The concept of a journey is so fundamental to our understanding of life and to our life in faith. Recently when I was at a wedding reception, I was struck by the different ways a number of people were repeatedly referring to how the two young people were starting out on a new phase in their life's journey. Whenever we try to understand our life or our calling or the little things that we may be engaged in day-to day, one insight that helps us to make sense of our activities, is to find meaning and purpose in what we are doing, in this concept of a journey.

How is a journey different from just going from place to place? If you think of people moving about, you would probably use three different words – if you just move about without a purpose you would call that 'wandering'. You may move about to see different places in which case you would call it 'travelling'. But a 'journey' is something more than wandering about, or even travelling. What makes the difference is that the journey has a destination. If you wander, you have no destination at all. When you travel, you have the purpose of seeing the places, and the surroundings through which you are travelling. But what makes a movement, a journey, is that it has a destination. It is in getting somewhere that the journey finds meaning and purpose. And this, I think, is the first lesson that the simile of journey of life can give to us. Our

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life's journey becomes meaningful, because of our faith, our calling and because He who calls us gives it a purpose, a direction, a destination. Therefore it becomes purposeful. Whatever happens during the journey, we still are sure that we are getting somewhere, there is an end point and that is the destination towards which we are directed.

Most of you would have had the experience of climbing mountains. Whenever I go to Kodaikanal I am impressed by the highest point in Kodai, which is the Perumal Malai. You can see it even from quite some distance from Kodai. Wherever you walk in Kodai, this is the highest point which is visible. I have climbed it a number of times. An interesting thing about this hill is that you can see the peak of the hill from the foot of the hill. However, when you start climbing, the peak disappears. Initially there are a few clear-cut tracks which a number of people have used. You only have to follow the tracks others have made. But pretty soon, the track fades off. You cannot see the pinnacle, there is no well laid track either and you have to find your own way.

This is often our situation in life. But what gives it a meaning and a sense of direction even in that situation is that you have seen the pinnacle, you know where it is and that direction keeps you going, even when the pinnacle and the tracks are invisible. Thus the most important fact about life as a journey is, finding its purpose, objective, and meaning, which God grants us through faith.

Throughout the Bible, from beginning to end, till we come to the heavenly setting, there are descriptions of a series of journeys. If you look at these journeys, you can see concentric circles within which they occur. In the beginning we have the calling of Abraham, one man called out from his people, not knowing where he was going. So it was very much like climbing the mountain. He did not know where he was going but he knew who had called him. That was his purpose. Even if he was in a trackless waste of life, so to say, he had trusted in the one who had called him. Again and again, we see this metaphor of journey in Abraham's journey, and Isaac's journey through life; Jacob's wanderings

and in his children becoming a people, the journey back to Palestine, successive stages upto Jordan, and beyond Jordan. We then come to the life of Jesus and the whole journey takes a new meaning. At various stages these are successive journeys by individuals, tribes, families, nations and ultimately the whole of humanity. I see atleast three concentric circles. One is the calling of an individual, as happened to Abraham and as happens to each of us in our lives. Many of us are associated with specific organisations, or projects or activities which is the second circle of journey. All that is within the larger journey of a community of believers and all the children of God.

One particular journey in the Bible which always challenges me is the journey of Paul, which he has recounted a number of times in his writings and in his speeches. I particularly remember the defence of his faith before King Agrippa where he concludes the story by saying 'O King Agrippa, therefore I was not disobedient to the heavenly mission'. It is that heavenly mission which he got on the road to Damascus which gave meaning, purpose and victory to all the small cycles of journeying and wandering that he undertook. Perhaps the most important point about a journey is its significance, its meaning, legitimacy and validity because of our destination and the calling behind it.

The second factor about journeys is clearly projected in the story of Israel crossing Jordan. Particularly in the small episode of them setting up twelve stones. The crossing of Jordan was a major point of transition in this larger story of the journey of Israel. The forty years of wandering in the wilderness and the death of Moses was the end of one chapter. In the next chapter—the opening into the promised land under the leadership of Joshua - God tells them to pick up twelve stones from the bed of the now-dry river Jordan, set them up first in the river itself, and after the people cross over, to pick them up and set them in the place where they were going, Gilgal. They were to do this so that those stones might be a memorial to their children. Whatever might happen in the promised land, all their struggles and uncertainties -

beginning with the story of Jericho and then during the exile - their children's children would remember the twelve stones which their fore-fathers had told them about. A physical memorial to their being called as a nation and to God's faithfulness in fulfilling that call.

In all our lives, at various points, God grants us these memorial stones. To Paul, one of the memorial stones was the important encounter on the road to Damascus. From then on there were further stones in his life. No doubt, there were numerous points in his life when he doubted God's calling - when his congregation proved unfaithful, during his persecution in jail, when people showed signs of unhappiness, signs which we find today in our churches too. But throughout his life, God had given him certain memorial stones to which he could look back and say, this is a memorial to my calling and to God's faithfulness.

We ought to remind ourselves always, about the preciousness of our own memorial stones. Not only in our immediate personal lives, but also the memorial stones in the further wider circles in which we see our calling - the history of our institutions, the history of our church and so on. The Church of South India, is very soon going to celebrate its 50th anniversary. A landmark point in its history. And perhaps, to many of us, as we look back on this period, we see a journey of triumph or a journey of decline. Whichever way we see it, this will be a time for us to look back. We may be tempted to question the validity of this Church of South India movement because of our disappointments and frustrations. We must then look back to those memorial stones which brought Church of South India into being - the early faithful of the century like Bishop Azariah and so on, who dreamt of unity, but never lived to see it; others like Bishop Newbigin, who actually made the unity a reality; the Faithful we have met from time-to-time within the family of our fellowship. These are our memorial stones which will help us, as also the individual experiences we have had, the times we felt called, during the times we were able to obey and when

through our obedience we experienced the validity of the call. We must cherish those memorial stones because these are the stones to which we can go back in the times when the track is not so clear, or is arduous and difficult.

Consider the word 'Gilgal'. I looked it up in the Bible and Gilgal refers to the movement of rolling, perhaps a rolling stone, or if we refine it further, a wheel or a circle. It is symbolic that at that point in the history of Israel there existed this small township which came to be called Gilgal, thus representing this movement or this circle of God's faithfulness which turns again and again in the lives of institutions, individuals, communities and the humanity at large.

It so happened that a few days ago, I was reading in the Reader's Digest about this very interesting marathon called the Annual New York city marathon. I am told that around 10,000 people run this race every year covering a distance of about 41 kms. All kinds of people run it - olympic runners at one end to most ordinary people at the other. I also read about one man who ran the race without any legs. His legs got blown up in the Vietnam War and he was moving on his hands. It took him a week to run the race, but he did it.

The important point, however is, everybody who completes the race is a winner. The winner of a marathon of that kind is not the person who comes number one. Instead, it is everybody's race. Each person runs according to his/her capacities and age. And everyone who completes the race is a winner. This made me think about the metaphor of long distance running. One interesting thing about running is that for people who start doing it, it almost becomes a profession, or a vocation. Again and again, they run by themselves or they join long-distance races. Some people actually spend their whole life participating in such races. My own son indulges in long - distance running. When I ask him about the psychology behind it, he says, 'I get a real high when I do it. If I am overworked I get away, may be in the darkness and go for a long run on the highway.'

Incidentally, in this long-distance running, actually you are running against yourself. It is not against anybody else, because the final outcome does not depend on which position you finish. The main point is, you finish. Every time you run, you are running against your past record. So each time, when you run a little better, you are a winner.

Very often, our life is similar. There are various points in which the pinnacle of Perumal Malai is not seen. Sometimes there is not even a track. All that you have is the little path you have initially, till you come to a corner, and then you don't know what it is. Many of us, especially young people, find ourselves in this situation. They know there is a God who has called them: they have their pillar stones in their lives which help them to continue, yet often there are phases when the path is not clear. Where am I going? Which is the next turn I should take? The choices almost look very similar. Very often I deal with young people who ask this question 'How do I make a career decision'. And my answer to them always is 'If you do not find yourself specifically called to a task, just be faithful to the task you find yourself'. To the best of your understanding be faithful in the situation you are in today, in that little distance you can see, as best as God would want you to. Surely, in that walking, you will find your track.

Therefore, a journey leads not only to a destination, but also into a quality of life. You do not know where you are going, but you know how you should walk. So it is not the distance covered, it is not even the direction that matters, but the way you walk - how faithfully you put one foot in front of the other and proceed. As you walk faithfully, your life unfolds. So that a faithful walk like this, is not only a journey to a destiny but it is a journey into yourself. You develop a certain quality, which is very valuable in Christianity. Often we ask ourselves, how am I doing? Our tendency usually is to look for external standards. We think of a grand plan we had planned and we ask, how is it going. Or we look at somebody else and say, My God, he is doing so well, where

am I? When you feel a sense of inadequacy, you may look at somebody else and say, oh, I am doing much better than that. In fact often we downgrade others, just to feel a little better ourselves.

But, as Christians one needs to always measure oneself against oneself. At the end of an year, ask oneself how has this year's walk been, compared to last years? Am I a little closer to the one who called me. If I am, then I am making progress - my projects may fail, I may feel frustrated, I myself may have fallen individually many times, but on the whole, in this whole inward journey into myself and to the one who called me, I see some progress.

So like Gilgal, it is a wheel, a circle. You repeat the circle again and again in your lives. Yet it is not an endless circle; it is a spiral. When you go round once, you come back to where you had begun, but at a slightly higher point. As you follow the spiral, you look back and say, with every circle, I am going up. This concept of a spiral of life is very helpful because we are often tempted to look at other people, other institutions and say, 'what is happening to me'? Instead look at yourself and see how the spiral of your life is working.

Consider now the story of the journey to Emmaus (Luke 24). Our journey is also a journey with a person. When Jesus called his disciples, he said 'come and follow me'. That call was about their route. He only meant 'Your route is where I go; trust me, follow me. You don't have to worry about the track. You only have to put your foot in my foot-print.'

Our journey in life is, thus, a following and this is a great consolation, because we have a role model. We don't have to worry about the route, or the journey. We just have to imitate our leader. He has gone through all our experiences. We have his assurance, 'all you have to do, is, follow me!'

As we follow this leader, we also realise that he is not only in front of us, but he is also by our side. He comes to us, as he came to the disciples who were travelling to Emmaus. Unknown to them, this companion joins them. Here we see

how this journey within a journey is playing itself out, within the journey of Jesus Christ. It is a narrower segment of the story of resurrection. Even if you don't consider the end point, just the journey itself is fascinating. A stranger, first becomes an acquaintance and then shares fellowship with them in the breaking of the bread. It is just like a person with whom you make friends on the train - he is first a stranger, then you start conversing about a variety of things and then you become friends with that person.

So, these are the four ways in which I would like to suggest that we look at this metaphor of a journey, pilgrimage. Firstly, we are not wanderers or travellers, but we are pilgrims, because we are journeying to a city of God. And within that journey we have the journey of our whole humanity, our church, our community and our individual journey. Secondly, in this journey, again and again, we have to look upon the pillar stones of God's faithfulness in our individual lives and in the various corporate entities where God grants us these pillar stones. Thirdly, we also have to look at our lives as repeated cycles, where, in a sense, we are running against ourselves. Again and again we pass through various cycles of experiences. But as we follow our calling, we are actually going up a spiral. And so without looking for validation elsewhere, we look at our own smaller journeys and see how with every circle, we are actually moving up. Lastly, life's journey is a journey of following our Lord, and is also a journey accompanied by Him.

In our discussion in the days to come, we will be presented with various challenges and new ways of looking at our calling within the Healing Ministry. But all of us who are involved in this ministry are also frustrated individuals. The last few years I have been devoting almost my entire time to standing outside the christian ministry, in the sense of not being a part of any programme or project. I have been spending my time more in observing what is going on, studying it, trying to find meaning out of it and finding out how to make progress. Like for most of you, this has been a frustrating experience.

Because we find so many failures and disappointments in our Healing Ministry, just as in the case of our church's life. But if we can look at it as a journey, in the various ways in which we have discussed, then we will be able to see God's hand working through us, working through our endeavours and through the endeavours of the Healing Ministry, over the generations. We would also clearly see that there is a golden thread of God's purpose which makes it a journey, and not simply a travel or a wandering. We will see in our institutions and in our various undertakings pillar stones which tell us that this is God's calling and that people have been able to fulfill God's purpose. In God's mercy He grants us in our own lives, through its ups and downs, a progress in our inward journey, into ourselves to find our true identity and our relationship with God.



REFLECTIONS ON THE FIRST DAY'S PROCEEDINGS

DR. M.C. MATHEW*

I have a friend who is a senior citizen. He told me something very interesting once. He said, 'when we grow old three things happen to us. One, we lose our memory. I forget the remaining two'. It is not necessary that we have to be senior citizens to lose our memory. It happens to all of us. Therefore this session 'Reflections on the previous day's proceedings' was included as part of the day's sessions to set apart time to quickly reflect as to what has gone on the previous day.

During this brief resume of yesterday, I will avoid referring to people who have brought these reminders to us, but I will try to pick up the strands that might help us in having a clearer view of the synthesis of ideas that evolved yesterday.

Let me approach it from three different angles. First, the history of the approach to rehabilitation. We heard from a number of people yesterday about the genesis and the evolution, of this approach, to the whole science and practice of rehabilitation. The origin was with people in the past and there was a number of references made to the approach and attitude of our Lord Himself. Jesus seems to have regarded people primarily and then responded to their need. His motivation was compassion, his desire was that people may be made 'whole'. Redeeming people from their state, whether they were physically affected or in otherwise difficult circumstances, was his passion for life. The approach of Jesus, therefore, lays the foundation that it is the will of God that his creation may be restored. The spirit therefore, in any involvement in the field of rehabilitation is this inner instinct to see people restored to their fullness. There was a good

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deal of discussion yesterday about the whole philosophy of rehabilitation. We seem to have gone through a journey of looking at rehabilitation from being charity-based to being challenge-based. We are no more invited to look and view people who are different from us from a point of view of being condescending in caring for them. But we are invited to regard them as a part of us, whose participation in our lives and our participation in their lives have a mutual strand, to enable us to grow together. That seems to be the challenge that is at the heart of the whole attitude to rehabilitation.

Each person is differently abled whether we use the 'd' at the end of the word or not. The emphasis that came through yesterday was that each person has an unspoken, hidden potential. So the first task that is before us is to have an optic to look at this hidden potential rather than be surprised/affected by the external fragility with which a person is presented to us due to his/her physically disabling situation. What makes this person, who is otherwise able, difficult to cope with? We have been told atleast by three speakers that it is their environment that makes it most difficult for them. Are we barriers for these people who are different from us? Is our environment so rigid that it makes it difficult for those people to keep going and achieve their potential? We who otherwise are well, seem to be in the majority and we seem to look at those who are different from us as in the minority. And who triumphs in this struggle? It is the majority whose needs are cared for. The minority who seem to be otherwise abled seem to get marginalised and neglected. So there came this inspiring question to us from few speakers as to how do we allow this minority community among us to have their say in the destiny of their lives.

Those who are different from us seem to be journeying through the desert of their lives. That desert seems to be hostile to them because others make it hostile. So when you go to visit the Spencer Plaza, the premier shopping complex in Madras, if you happen to be having a pair of crutches or happen to be on a wheelchair or if you happen to be visually

not very well, you will have no access to that multi-storeyed building. A typical example of the hostility because of which people who are different from us are often discouraged and deprived. So came this question 'how can we help the desert to bloom?' The answer was not evident and yet the parable of the mustard seed was presented to us as a moving story of how the smallest of all seeds grows to become a larger tree in which the birds of the air can come and rest. The least among us, the so-called weak, the people who are deprived and denied of many opportunities are perhaps like this small seed. When given the opportunity, encouragement and support they grow and become a larger blessing for people around.

So in this whole approach to the history of rehabilitation there came this vivid challenge to us of looking at people who are different from us not as people who are somewhere else and to whom we have to provide services, but to regard them as very much a part of us because in Christ Jesus there is no Jew or Gentile, no male or female, there is no abled or disabled. We are all one in Christ.

The second dimension I want to bring to you is the story of some of the models that have been evolved. We were presented with a few models, yesterday, of various approaches and practices of rehabilitation. The one that received a good deal of emphasis was Community Based Rehabilitation (CBR). And in that, I thought, there were two parallel models presented to us. One is an approach largely initiated by multipurpose workers - people who are trained in various disciplines of rehabilitation and who integrate that in their approach while involving themselves in the community. And that approach seems to be the most appropriate in our rural settings; that also seems to be meeting a need in a significant way in the various parts of this country, in the last 15 years. We as those belonging to the family of God will realise that the church was also in the forefront of this approach. The other model in CBR as presented to us, is an inter-disciplinary approach where people trained in various disciplines work together in order to focus on those with special needs.

Whether we use a multi-purpose model or an inter-disciplinary model, the desired outcome seems to be enabling those in the community to respond to their own needs. And I thought that there was an overt as well as a silent reference to this whole issue of enabling those who are different from us to participate in the decision-making of their own destiny. The tendency on the part of the professionals to decide as to what is best for someone who is different from us can be sometimes so overbearing that people with special needs become passive, silent, and beneficiaries rather than active participants in the choices and decisions they are called upon to make for their future. So we have been reminded that all forms of community based rehabilitation ought to have this active ingredient of helping people make their decisions rather than letting decisions being made at the state level and the national level. The community then becomes a theatre of activity. Community becomes a venue, where people meet with themselves to find answers for their own quests for a better tomorrow.

The third dimension I would like to refer to, is the emerging scenario in the country. In this section I want to refer to two factors - one, the initiatives that those who are different from us are taking globally, nationally and locally. We had a person here yesterday who has visual impairment and a person who has hearing impairment. The person with visual impairment is a Professor of Theology in a leading Theological College, and the other person has recently brought out a very innovative magazine called 'Ability'. They are advocates reminding all of us that people with special needs are capable of achieving lots more than what we think they can achieve. So we are moving in a direction where people with special needs are taking the initiative to respond to their own needs. We have a person who is quadriparetic in New Delhi, who, again, publishes a very innovative magazine called 'Voice'. I have come across atleast 22 organisations in this country headed by people who are otherwise, themselves abled. We have organisations chaired by visually impaired people,

physically impaired people and people with hearing impairment, indicating that the initiative on their part is on the increase because of which, as in other parts of the world, in the future they are likely to decide what their need is and how it shall be met. This is a reminder to us, as professionals, because thus far we have decided what they should be, how they should proceed and what they should become. Now they are telling us, 'Leave the choice to us, we turn to you when we need you; leave the rest to us'. And there comes this important dimension of partnership.

The second factor in this dimension is the frame of reference for rehabilitation. The frame of reference is the local community, the local congregations. The Church is a healing community. The local congregation is the visible expression of this mission of the church. How far is the local congregation involved in responding to the needs and challenges of those who are different from us. In fact, this consultation drawing together people from various sections of the church—the clergy, the professionals, the laity and the leadership – presents an important scenario in which we shall now find ourselves placed in the future. When congregations become awakened to the needs and opportunities that are before us in involvement with people who are otherwise able, we enter into a new territory. The church has a long tradition of being involved in the healing ministry and we have a long tradition of being involved in the care of those who are otherwise able. But the participation of the congregation and its role of bringing about changes have thus far been not so adequate. So the frame of reference to any form of rehabilitation, as we look at it from a christian point of view is the local congregation.

I have presented before you three dimensions which I thought was referred to by various speakers yesterday in our deliberations—the history of our approach, the story of some models, and the emerging scenario with initiatives from those who are otherwise able, the frame of reference being the local congregation.



AREAS OF UNMET NEEDS

PROF. ZACHARIAH*

The title gives me my opening point—our understanding of ‘unmet needs’.

What is our concept of unmet needs? As soon as you hear the words, all of you who are interested in the field of rehabilitation in some form or the other, would have a certain mental picture of things which you feel are ‘unmet needs’. But to focus your ideas, I would invite you to look at the life of Jesus and ask the question, what were the unmet needs He met? To us who read the gospel story, some of the unmet needs He met would be that of the tax collectors, the prostitutes, the leprosy patients—those who were not on the agenda of unmet needs of the society of that time. But those were the needs He met. But how did society see them? They were also sensitive, conscientious people. How did they perceive these issues? To them these were unsolved ‘problems’, to cope with, for which they evolved certain strategies and ways. To a great extent, the coping mechanisms were legalistic. For instance, the leprosy people had a certain way in which they were to behave, that was laid down in the rules of society. So also the way one looked at prostitutes and dealt with them. If you look carefully, you see that in every society there are unsolved problems which we think about as ‘issues’. We produce conceptual ways of handling them—ways which are comfortable to society, usually by laying down rules, programmes and protocols. But to Jesus, these were unmet needs and He responded by caring. I think that this difference can be quite useful to us as we ask the question, what are the unmet needs?

The particular group about whom I would like to speak is perhaps a group which we don’t think about immediately, when we talk about those who are differently abled or when

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we talk about rehabilitation. But infact, they are a large group of people. I refer to the *elderly* among us. The people who in their older years develop disabling diseases like strokes, myocardial infarction or joint problems. Otherwise very fit individuals, but whose lifestyle is completely changed because of osteo-arthritis and degeneration of joints, which certainly change what they can and cannot do. I will also try to include in this group of people with unmet needs, people with terminal illness, renal failures, cancer and, in the coming years, AIDS.

The first point I would like to make is that the reason for this group becoming increasingly important is the success of our own health care measures. Today people live longer and people who develop various diseases can look forward to many more decades of life. Especially people with the so-called terminal illness today have increased years of life. It is the success of our own abilities that these people can stretch out the years of their lives, can partly overcome diseases which were in the past fairly abruptly terminal. This is really what has given rise to this large group of people with unmet needs.

Some of you may have seen a little note in the newspapers a couple of days ago to the question of monarchy in Britain and the prediction that Queen Elizabeth may be monarch for another 20 years. By the time she steps down, her grandson might be quite ready to become a king. This prediction is based on facts—looking at her age, her health history and her family history. This is the kind of life which is ahead of many of us. With the lifestyle and health care facilities that are available to us the evening of life is becoming a long afternoon—a process of slow decline. Most of us, after retirement will have many decades of life. And so the question is, how do we make these years hopeful?

I also want to emphasis that this perhaps is the largest rehabilitation programme, because, as the whole profile of the society changes, slowly but steadily, we are moving towards the pattern of older societies where the bulk of the people were those in the post-adult years. And it is, therefore, their problems that we are talking about. We can be sure that the

problem would only get worse, because as more progress occurs more and more of these problems will arise. People will live longer, many diseases which were considered terminal, will not be terminal or the terminal stage will be spread out. Therefore we can expect that as our society advances, this problem will become major.

What actually is the challenge before us ? I think the challenge is at different levels. One part of the challenge is a change in the attitude of society to this group. Traditionally in our society, we have looked at this group in exactly the same way we used to look at the group which we call 'handicapped'. If you had a handicapped person in the family the family tried its level best to 'take care' of that person. We were as kind as we could be to that individual. But it has always been an attitude of 'taking care of' that person. The whole transformation that has taken place in the history of rehabilitation is the new realisation that these are not people who need to be 'taken care' of, but these are people who can also lead whole, full lives. So it is that enabling or mainstreaming which is really the attitudinal change in the whole history of rehabilitation.

From that perspective, if you look at the elderly, we face a problem. Because when we have a handicapped person and when we classically think of rehabilitation, we think of a well-defined group like those with physical handicap, mental disability and so on. They are easily identified because they are obviously different from the so-called normal people. And often these disabilities are identified in the early years of life or in the adult years. But we are talking about people who have passed their adult active years and whom we may now have to think of as those we need to take care of. But now they are going to live even decades after they have reached the 'taking care of' stage.

The note we then have to make is that they are also differently abled people. The elderly are people who have already passed through their adult life and they have well-developed abilities. But they have sort of failing physical

energies and perhaps mental energies which make them a little different. But they are not people who need to be taken care of but people who should now be enabled to be in the mainstream of life, and not at its fringes. The velocity of the stream has been pushing them to the side. They should be enabled to make their full contribution to society and many of them have much to contribute with their vast experiences and vast skills.

If you go to any gathering, a wedding for example, you will notice that 50% of the conversation of the people would touch upon the 'problems' of the elderly--about parents, grandparents etc., who had to be taken care of. They are not 'problems' to be solved but are quite able people who must be enabled to make the change so that with their new types of abilities they can be in the mainstream.

The second change that is needed is in the differently abled people themselves. Because this is the way society and the family look at them, they also think that they are no longer in the mainstream. This person who cannot move about easily because his/her hips or knees have failed, now thinks that he/she too is disabled and his/her proper place is in the rocking chair at home. But what about all the abilities that this person has? For instance, she may have been a very able teacher and so has all the teaching skill and wisdom she can now impart through tuition classes, for example. So the challenge is in enabling these persons to reschedule their lives, to look again at their skills and not at what they have lost but at what they have and how these can now be fruitfully applied.

That leads to the third challenge, which is reorienting these people so that this transition actually takes place. An attitudinal change can create situations where the individuals can also change their attitudes and can become effective members within the mainstream, with lots to contribute. One great advantage with these people is that they can contribute without asking for any reward because for most of them financial support is not the criterion. With all their skill and experience they are usually available for voluntary service or

for a nominal honorarium. But the main challenge is to help them to see what they can contribute to society, to see they are maintained in the main stream and then for all of us to see to it that we create circumstances in which this transition effectively takes place.

If you look at it in that angle, then you see that the main change has to be in the community so that it becomes basically a challenge to the community. Nowadays all our discussions on rehabilitation concentrate on community based rehabilitation. To a great extent, when we talk about CBR, we are talking about rehabilitation by the community. But I would like to suggest that, in this group, we are rehabilitating the community itself because their elderly are a significant part of the community and they will continue to become more significant. I would like you to look at this term 'Community Based Rehabilitation' in a different way. Not simply that the rehabilitation measures are carried out by the community but that the challenge is to rehabilitate the community itself. In enabling the older members to come to the mainstream, in a sense, one is rehabilitating the community as a whole. So it is community based in that sense.

It follows, then, that the ideal setting for helping these people to be whole and wholly participatory in society is really the congregation's role as a healing agency. This is perhaps the ideal matrix where that role can be played out, where the congregation and community can play its part in helping to meet the needs of the differently abled. Needs cannot be met by institutional efforts but with a whole-hearted response from the whole community. The elderly people were once participants in the community, now they have lost certain abilities which had enabled them to function fully and to contribute their share to society. And so it is the duty of the society to restructure itself to some extent. It is a challenge to the community to organise itself so that the people who have developed disabling diseases are helped.

Very few communities have achieved this. One group of people with whom I was very impressed is a group in Canada,

where the whole society is geared to the fact that the older citizens, should have full privileges. For elder citizens the public transportation is totally free, and so also in all amusement places, museums etc. They recognise that these people are a large and important part of society and that they must be able to participate in life. If you look at it deeply you will find that when we go through this process, we are also rebuilding community.

So on the one hand, this is an ideal setting for a community/congregational response, but on the other hand what we are undertaking is community rebuilding. Often we talk of what the society can do to incorporate them, but what I am suggesting is that actually when these people are incorporated we will have a different society.

Let me bring to your notice two specific dimensions to this whole issue. 'One is to ask ourselves as members of the congregation, 'how is our congregational structure to be rebuilt', in the way I earlier mentioned (of a community response while becoming a different community) 'to what extent are our churches and congregations doing this.' When I look at that, I see that all our congregations have Sunday Schools, Youth Groups and Women's Fellowships. Aren't the elder citizens also believers? What contribution are we making to the spiritual concerns of this large group? Certainly many of the older citizens of our churches have over the years, as they grew in age, have sort of been eliminated from the congregation. So I would like to ask all of us as members of the congregations, how do we bring them into the mainstream? We have identified children who need to go to sunday school, we have identified youth who need to be confirmed. But what is the place in the church for this increasingly large group of believers? How do we keep them as part of our spiritual fellowship, and help them make their contributions ? There are families which face problems of raising children, of marital discord etc. These people with their wisdom and experience are the ideal counsellors. But we do not recognise their value. They lost our fellowship, we lose their wisdom.

The second dimension I want to refer to, is from an institutional point of view. How do we take on this pioneering role in our hospitals? We have, in our health-care institutions, different departments-paediatrics, obstetrics and gynecology etc. There we deal not with individual diseases, but with segments of society. We have identified that children are not just small adults but a different group and they need different kinds of doctors. So also with problems faced by women.

But what about this increasingly large group of elderly people? There exists diseases like myocardial infarction or cerebrovascular accident or osteo-arthritis. We only think of them as diseases. But here is a large group which has its own human problems. So at the institutional level, our Christian hospitals and health centres can identify and decide that we will have a designated focus on this group not merely in a technical sense solving their particular disease or problems. And when we do that, two or three interesting things happen. One, of course, is that we will become more community based. If we look at the history of our mission hospitals, except for a few that have become national hospitals, the majority of them after a first few years of their lives become community hospitals. As a church hospital establishes itself, it becomes the community's hospital. But as the hospital progresses, the hospital says that individuals from the community can come here for their episodic illnesses. So gradually the hospital moves out of the community, even though for the people, it is still the community hospital. But if the hospital has its focus on this group, inevitably you will find that the hospital is regaining its position as a true community hospital. This is then an emphatic way of making our hospitals and health centres community based and community owned. We will thus belong to the community because every family faces this challenge sooner or later. And at the moment there are no other resources.

One example from my own experience-my home town is Thiruvalla in Kerala, a small town with lot of educational institutions and many hospitals—infact it has four 200+ bed

hospitals. But if you are an elderly person in Thiruvalla, you have had it! It is a paradox that even with so much facilities, well-to-do, affluent educated people have a miserable end. I know a cancer patient there, her husband is a health professional and with children being in America they have no lack of money. But she could not get medical care and every month her nephew a doctor in Bangalore used to go to Thiruvalla to take care of her. I am sure many more families can cite similar stories. If our hospitals take this task seriously we will be addressing a felt need of the community.

Secondly, since these people are mostly in their homes and it is difficult for them to get to the hospital we find that the hospitals will go into the community. Once we take this group with unmet needs seriously, we will not be able to sit in our hospitals and operate only from there. So, then we will find that the hospital will not only belong to the community but will move out into the community.

Thirdly, as we do this, we become 'agents of change' in the community. Because taking care of this group is a matter of changing the society. So if Christian health centres take leadership in this, not only will they be undertaking a pioneering task but will be causing the kind of transformation that we are struggling to achieve.

Therefore, if this large area is seriously addressed, we will rediscover the place of mission health centres in the society-they will become true community health centres, will move out into the community where the problem actually exists and then will effectively change various facets of the community.

To conclude I would suggest that our task is not so much to go into practical issues but to recognise that this group, which we never thought of as differently abled, is perhaps the largest group we need to consider. What is mainly needed is to bring about an attitudinal change in ourselves, help these people to have an attitudinal change in their personal lives and in the process, to change society itself.

LEARNING FROM WHAT THEY ARE

DR. M.C. MATHEW*

About 10 years back, someone gave me a poster with the picture of a rose flower. Below that, the caption read, 'YOU HAVE TOUCHED ME AND I HAVE GROWN'. Because I like rose flowers, I fixed it on a cupboard opposite to where I sit. I used to look at this poster and read the caption over and over, wondering what is meant. Having waited for 8 years and not having found a clue to what is meant, I decided to take a still closer look at it. So I opened all the windows of the room, shifted the cupboard slightly to the sunlight and then, to my surprise I discovered that the picture had become richer. In that bright light I could see that the artist had meant, in his original drawing, that the sunshine should fall on it. In fact, there were traces of sunlight on those rose petals. In the bright sunshine, I noticed that, on the petals, there were also gentle drops of the morning dew. Then it began to make sense to me. I realised that the artist had in his original drawing, meant that the sunshine had touched the flower, and the flower had grown.

This particular thought then began to linger in my mind. By then I had spent around 11 years or so with children who had various developmental needs. During those 11 years I had been involved in doing many things for them. Children were referred from various parts of South India to the place where I work, and my responsibilities had been to do a developmental assessment and to be involved in various ways of providing support to the child and to the family, in his/her developmental process. And I thought I was doing a marvellous piece of work. I took a lot of encouragement and enjoyment from what I was doing and I had a sense of fulfillment.

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But when this particular thought came to my mind whether these children were a sunshine to my heart, I began to wonder. My position has been that of a care giver, a provider for them. Having spent about 10,000 hours and having had about 5,000 Consultations until then, what have these hours of involvement with children and their families meant to me? Some children have been coming regularly for 11 years. Having been involved with them so intimately and having been associated with the dynamics of many families, WHAT HAVE THEY MEANT TO ME? Have they become sunshines in my heart? WHAT AM I LEARNING FROM THEM ?

To me, and to my wife Anna, the last two years have been particularly a journey of new discovery. A discovery of finding meaning from what they are to us.

Let me now take examples of three children to illustrate to you how we ourselves are learning from what they are to us.

Annie who first came to us when she was just a few months old, has had several needs. She suffered from cerebral palsy, and needed a lot of help. Annie's family, especially her mother, was involved in various kinds of support to her. The mother helped her in providing passive exercises and Annie herself participated actively in these exercises. Little later Annie was able to receive further help from ASHIRVAD, where she was introduced to various skills of pre-learning. But a few months later Annie fell sick and developed progressive primary complex. She recovered from it remarkably and was subsequently prepared for school by employing language stimulation and by being introduced to pre-reading and pre-writing skills. She was encouraged to sit, to stand and do other basic functions.

At that time the family went through a lot of difficulties. The father and mother had to move away from the heart of the city because the father lost his job and so had to find a relatively cheaper house. This led to a series of inconveniences and Annie stopped going to school. Because of this she had

to adapt to a new mode of transport, the wheel-chair. Yet Annie seemed to triumph in that situation. Although she had difficulty with their hip, knee, hands and bending of the spine, Annie continued to communicate her radiance, which I suppose was from deep within.

The family at this time faced another setback. The mother who had hypertension suffered from mild anginal attacks periodically. She was slowly becoming incapacitated to give Annie the attention she needed. This led to Annie getting slightly isolated from the family's involvement. Yet, when she visited us on her birthday that year, she looked very cheerful and was jubilant with the gifts she received and the song everybody sang for her.

But Annie's story took a different turn, when she had a flare-up of tuberculosis. In spite of this, Annie kept up a high profile of encouraging others.

At this time we happened to visit her home on a rainy evening. As we stopped the car and were about to get into the house, we heard someone laughing very loudly. The mother having seen us through the window told Annie that we were visiting her, and she was tremendously excited. We found that Annie was increasingly declining in her health. Yet her beaming smile brightened our hearts, as always.

Annie's story is a story of many triumphs in trial, for the family and the child herself. Her relatives, friends and neighbours tell us that she is a silent encouragement to many people. Her home in the community is a place where people come to visit her and draw inspiration from this girl who is now 13 years old. She spends all her time in bed, but with a radiant smile, announcing the Good News that within her resides the spirit of God which cannot in any way be thwarted by the fragility of her body. Fragile, she sure is, but she is a silent announcer of the Kingdom of God.

Annie has touched all of us at ASHIRVAD because she announces TRIUMPH IN TRIALS.

Zafeer was first brought to ASHIRVAD when he was 6 months. He was referred to us from a neuro-surgeon in England, with a letter saying that the child had just undergone a surgery for Hydrocephalus and had a shunt put in. We were asked to provide whatever support was possible and to offer neuro-developmental support for Zafeer. Over the last six years, along with this family, we have been involved in giving Zafeer various neuro-developmental stimulations. Zafeer, at about 9 months, developed a slight squint which became really pronounced by around 12 months, because of which he was not able to see very clearly. So many activities he had to carry out to promote his development could not be carried out. This also had affected his visual fixation. So by the 14th month, he had his first surgery for the squint.

Zafeer was an adventurer from that time. To all developmental stimuli he responded positively. Although he had some weakness in one side of the body, he was able to crawl. With his determined efforts and with the support of his family, Zafeer was able to succeed in basic activities of day-to-day life, like reaching out and picking up a book. His achievement so far is a proclamation of his feeling, 'I MAY HAVE MANY STRUGGLES, BUT I DO HAVE MANY STRENGTHS'.

By the time he was 18 months, Zafeer had the second surgery for his squint after which he was able to fixate well. But we noticed by then that one of his ears was not functioning normally. The family was encouraged to provide extra help to promote his hearing skills. We discovered during our regular hearing screening that Zafeer was not listening to sounds below 60 decibels. This confirmed that he had only a partial response in one ear. In order to help him, we introduced the family to various forms of speech and language stimulation and they involved themselves in providing help in his articulation, association of words with pictures, association of ideas with action and so on.

Time lapsed and by the time he was $2\frac{1}{2}$ years old, we had to suggest that he be given a hearing aid. Because the

family had connections in the UK, they were able to get a post-aural hearing aid which was very effective and appropriate for Zafeer. He thus made yet another stride in preparation for school.

While at School, children are required to write, but Zafeer, because he had a mild hemiparesis on his right side was incapacitated partially. His holding of the pencil was odd. So we provided exercises to improve his co-ordination and skills of writing. We were surprised by the way Zafeer spent long hours at home, helped by the family, continuing the exercises. By the time he was 3 years old, he was ready to write what was required of a three year old child. His co-ordinating skills also had tremendously improved.

Zafeer through all these struggles set his goals 'high', thanks to the family and with support from ASHIRVAD. Zafeer had to a certain extent, become independent by then-he could put on his shoes, tie shoe laces and so on.

For a child who has had two operations between 1 year and 18 months, hearing impairment by 2 years, hemiparesis and a number of other medical illnesses requiring hospitalisation, Zafeer's struggles were far too great.

By 5 years, Zafeer had come fairly well out of his struggles and was now ready to join a normal school. But the schools would not accept him. They said, 'How can we accept a child who has these problems' ? We decided to speak to one of the leading schools and placed before them a challenge. We told them, 'here is a child who has tremendous resilience, whose family has a tremendous capacity to care and support. Won't you welcome him and be surprised by what he can do.

Zafeer joined School. After 3 months, his father met with a nasty accident. He had multiple fractures and injuries of the skull, both his eyes were badly damaged and he was in hospital for three months.

The hand of God has been upon them. He has recovered from the fracture with no neurological deficit. Zafeer continues

to linger on with stress, both from home and school. The last report that we got from a teacher in the school is again a story of the strengths of Zafeer. She said 'Zafeer is our model child. He often thinks of others. He takes care of other children who have special needs. When someone is sick, it is Zafeer who enquires after his health. When someone does not come to school continuously for a few days, it is Zafeer who telephones and finds out what is wrong and when the child returns, it is Zafeer who welcomes him'. The teacher concluded 'ZAFEER TEACHES US TEACHERS WHAT IT MEANS TO CARE'.

Zafeer is in that school as a messenger, to announce to this broken world marred by competition, strife and tension that at the heart of every human being there is this invaluable possession of caring for others. Zafeer lives for other children. His strength is in taking care of others, even if he appears imprisoned in his body because of his fragility.

Puneeta reminds us of CHANGE IN THE MIDST OF CHALLENGES. Puneeta has had Turner syndrome, a chromosomal dysfunction, Hyperthyroidism. We saw her first when she was six months. Shortly we noticed that she also had mild hearing disfunction, with hearing capacity of about only 50 decibels. Puneeta is the first child to a young couple from a lower middle income family. For the family, this was a devastating experience. Children with Turner syndrome tend to be slightly obese. So the family often faced this unpleasant question, 'Why is your child so obese?' They were haunted by such questions. At ASHIRVAD they had more tears than words. That did not mean the family gave up. With treatment for hyperthyroidism and with stimulation exercises Puneeta's condition improved. She was able to sit by around one year and to stand with support by 18 months. She began taking small strides towards walking. Thereafter because she was obese, she did not succeed much and was often in a crawling position. However, her neuro-developmental process was also very encouraging.

By the time she was 2½ years old there came this very challenging question from the family to us: 'What about having another child'? This question from a young couple was a daunting question. Although the chances of recurrence of Turner Syndrome is not high, there is no predictability. We had wide discussions with colleagues within India and abroad as to how to proceed. The consensus was: nothing can predict the recurrence or the absence of the syndrome. Discuss with the family and decide.

We spent long hours with the family discussing the decision and how to face the situation if the child was to have a special need. After about 6 months, the couple confidently told us, 'We are ready for a new baby'. By then Puneeta had joined school. She had difficulty there but she was coping well.

Soon the mother conceived. The nine months of pregnancy were periods of anxiety, concern and sometimes fear. The father and mother went through the process of preparing for the baby, while Puneeta received help both at the school and at ASHIRVAD.

What a delight it was to us when the family rallied around the mother towards the end of the pregnancy and when she delivered the second baby-a perfectly healthy baby. The arrival of this baby has meant so much to Puneeta.

Change in the midst of challenges. What were the challenges to Puneeta ? She had hearing impairment and hyperthyroidism. She was ugly to look at when others saw her from the point of view of external beauty. She had difficulty to move about and had to endure harsh comments in school. What was the challenge before her parents? The difficult question of whether or not to have a baby; nine months of suspense... so many challenges. Yet, the family has been so transformed. To us, this family has been a family that stays together.

I regret to say that only during the last two years have we been given the grace to understand the blessedness of

being in the company of these children. Although the earlier years were not years when we could recognise this dimension, we now praise God for the gift and grace that has been given to us. To us, they have become like that rose flower in the picture whose caption read, 'YOU HAVE TOUCHED ME AND I HAVE GROWN'. These children and their families have become sunshines in our lives. Learning from them is a process of growth and development for which we are grateful to God and these families.

Let me close by reminding you of stories of triumph in trials, strength in struggles and change in the midst of challenges. We are learning to move into the realm of receiving rather than giving. We continue to receive from the giver of gifts, God Himself and from these children and their families-they are a light unto our path and refreshment in the course of our journey.

I believe that all of us who are involved with children having different needs, can have the blessing of their presence in our lives and in our midst, because God has chosen the unpleasant things of the world in order to make them a blessing to us. We who believe in the goodness of God will continue to see the goodness of these children and their families.



HEARING IMPAIRMENT

DR. SR. RITA MARY*

If we consider the attitude of the church in the early days we see that it has not been very favourable to the differently abled. They sure have been given protection for a safe life, but were never made participants in the community life.

In the 16th century, monks employed deaf and dumb people in the monastery, in order to maintain silence; deaf people could never disturb! In the 17th century, there was an awakening in the church about taking care of these people. It was decided to provide some kind of christian education in order to inculcate christian values in them. They were taught catechism, were given communion and they took part in the sacraments. But they were told that they cannot participate in the church activities and in the community services within the church. They were only allowed as observers, looking at what is happening in the church. Then came individuals, many of them religious leaders, who believed that these people need to be trained and prepared before they could be integrated into the normal stream of society. That is how the first National School for Deaf came into existence in Paris. Slowly the concept spread to UK and United States. Since it was assumed that intellectual abilities of those with hearing needs did not allow them to take up many of the available jobs, they were given monotonous jobs just sufficient to find them a living. Later people realised that the 'dumb' people are not inferior mentally but have only a certain amount of hearing loss and so can be educated, trained to speak and made to participate in societal life. This led to the present situation, where those with hearing impairment participate in all spheres of life.

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When I did research for my Ph.D. on the 'Role of Christianity in changing welfare activities for the Deaf', many of my findings surprised me. I happened to read that St. Augustine once remarked that the disabled people are a curse; they cannot be taught even religion because they cannot comprehend it. On the other hand it was also felt that they were not responsible for their own mistakes because their mental faculties were not normal.

Today the situation is different. Due to scientific developments, 90% of those with hearing impairment can be trained to lead normal lives and can be integrated into the mainstream of society. But does this really happen? When I entered this field around 27 years ago, I found that there was a growing feeling that providing residential facilities for the deaf would be the right thing to do, especially in the South, with christian societies running many institutions for those with hearing impairment.

'Residential care' has come about as a result of the attitude that we need to 'provide' them with good food, good shelter, good health care, good clothing etc. While in the earlier days Residential Care was the only type of care available, today it exists parallel to day-care centres. In day-care-centres, children show better improvement than those in residential centres. This is mainly because when children with hearing needs reside together, they form a sub-culture. They think this is their only world and nothing else is open to them. But when they are introduced to others, this attitude changes and they strive for more.

In the recent past higher education facilities have been made available for those with hearing impairment. I have found that those who have made full use of these facilities have actually been able to contribute much to society, and not remain parasites on the society. They earn their own money and pay their own tax. For example 17 of my old students are now holding positions in the Indian Overseas Bank. It has been found that 5% of those with hearing needs today avail themselves of higher education facilities available to them.

The next obvious question then is, why only 5%? The primary reason is that still a majority in our society believe that these people are not capable of higher levels of education. And so, disabled children whose parents entertain this attitude, are not motivated enough to aspire for more. Thus they are denied of the education which today provides them with a lot of opportunities.

National policy on Education states that the differently abled should be integrated into society as much and as early as possible. In other words they have to be given equal opportunities. This would mean that children with hearing impairment can be sent to 'normal' schools/colleges so that they learn the same subjects and undergo the same courses as 'normal' children. This is possible only when certain modifications are made in the administration of educational institutions. Because many of the children inside our campuses become victims of the administrative stagnation, only a change in this would lead to integration of disabled children in our institutions and thus in society at large.

The community has to be educated to take the responsibility of integrating the differently abled. Today we find difficulty integrating children in schools because the schools still do not believe in integration. Although in 1974, the Ministry of Welfare formulated a scheme for integrated education, even today most of the schools do not come forward to accept children with hearing impairment. Increasing awareness among teachers, and principals is very important.

The consequences of denying education to the disabled is enormous. It may not be a problem during their childhood days. But once they grow old and have to depend on their siblings and their families, problems arise. This leads to a wide variety of other problems-emotional, psychological etc. Education is the best answer. An educated person would be able to stand on his/her feet and not be totally dependent on the family.

Early identification of the impairment is essential to initiate the best education and training. With advancement of

technology, this is very much possible. Nowadays even three or four month old babies can be identified as hearing impaired, whereas in the olden days it took around eight or nine years before the impairment was identified.

Therefore it is important that professionals make an effort to reach out to the unreached population. For, by the time parents recognise the impairment in the child, it might be too late for correction. Total correction is possible if the impairment can be identified at its early stage. A step we have taken in this direction is to go to the hospitals, maternity wards, etc., and with special permission, screen the babies to find out if they have proper hearing abilities. Through this programme we are able to identify 'at-risk' babies-from family backgrounds, from medical history of the mother during pregnancy etc., and then we conduct periodic follow-up programmes so that these babies are given the best services at an early stage. If we can train the children during the critical period of 0-2 years of age, most of them are able to attend normal schools at a later stage.

However, this does not mean that we have no need for special schools. Special school education and integrated education should grow parallel to each other. This would ensure that those among the hearing impaired who are capacitated enough for normal education can go to 'normal' schools and at the same time those who need special education are provided that in an effective manner.

Once the impairment is identified, efforts should start immediately to train the child, mainly by making use of the mother as a teacher. (This programme called the parent-infant programme is being implemented now at the national level.) The professional works with the child till the child is ready for school. This period can be so critical that if properly utilised the children can go straight to normal schools. If that is not possible, the child can go to a nursery in a special school.

The main disadvantage faced by those with hearing impairment is their language. Since they cannot hear, they cannot speak. So we need to help them with other methods of acquiring language. For this, the pattern of residential care should change in such a way that the number of resident children is limited, care-takers are increased and cottage-system is implemented instead of large institutional care models. It may involve more financial assistance, but this will be a more effective method.

Then what about the hearing impaired children in rural areas? Using CBR programmes, the facilitators work with the mothers, the gramasevikas, the anganawadi workers etc. The model of care for people in rural areas is different from that of urban/semi-urban areas. A community based programme is best in a rural set up.

The degree of hearing loss varies from person to person. Depending on that, the person's training should vary, and his/her development will take place accordingly. Awareness among the family is yet another factor which contributes to the training programmes of the child. Fortunately more and more parents are now aware of the problem and so are coming forward with a positive outlook to their children. But in the semi-urban and rural areas this awareness is considerably low even today.

Let me now bring to your notice the different terminology that is used in this field. When I started my work, the hearing impaired people were called 'deaf and dumb.' Even the name-board of our school said 'School for the Deaf Mute'. Till last year the school I worked in, in Bombay was called School for the Deaf and Dumb. Both these words deaf and dumb go together always-as cup and saucer or table and chair!! We forget that they are 'dumb' because of their 'deafness'. Once this was realised and the children were given training in this direction, they were no more 'dumb' but only 'deaf'. And once they were given education through other methods, they were no more deaf, but had ways of communicating.

Fortunately these days the terminology has taken on a more positive stance. We hear words like hearing impaired or hearing handicapped. A positive terminology will lead to a positive approach.

Looking at the training facilities for those with hearing impairment that are available, we see that throughout the country there are 500 institutions ranging from small schools to higher educational institutions. In the South there are only two colleges-one is the St.Louis Institute for the Deaf and the Blind-the first of its kind in India, started two years ago. In Valakom (Kerala), there is a study centre which facilitates the Indira Gandhi Open University education programmes. There is a great need to give continuing education and adult education to those with hearing impairment so that their educational level is improved.

If you look into the employment level of the hearing impaired you find that majority of the hearing impaired persons are unemployed mainly because they have not received the education and training they need, leading to low levels of aspiration and ambition. With proper community education, I am sure 80% of the hearing impaired can be given proper education and can be integrated into society.

A significant aspect in providing the right education is to get the right professionals in training. I, who have been involved in teacher training programmes for the hearing impaired have very often seen that the teachers do not strive for more, than the level of training given to them. A good teacher is also a good learner throughout his/her life. This is specially important nowadays with medical and technological advancements taking place at a very fast pace. Unless something is urgently done to keep up the quality of professionals the education of the hearing impaired will suffer.

In conclusion, let me remind you that more than all these, it is important to remember that prevention is better than cure. Awareness programmes are most essential to spread the message of prevention.

SPECIAL NEEDS OF THE DIFFERENTLY ABLED

BR. DEVASY MADAVANA*

‘He that is stricken Blind
cannot forget the precious treasure
of his eye-sight lost’

—*Shakespeare*

Disability : A disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Blind Person : A person with no perception of visual stimulus is totally Blind.

Visually Handicapped : A person who suffers from any of the following disabling conditions.

- * Total absence of sight.
- * Visual acuity not exceeding 6/60 or 20/600 (Snellen) in the better eye, with the correcting Lenses.
- * Limitation of the field of vision subtending an angle of degree 20 or worse.

‘Blind persons are just like other folks
Except that they do not see with their eyes’

—*Allen H. Eaton*

Blindness in children may be caused by maldevelopment or damage to different parts of the eye, the optic nerve or the visual nerve pathways to the occipital lobe.

Abnormal genetic endowment may account for abnormalities in any part of the visual apparatus—cornea, lens, iris, retina, choroid, or optic nerve pathways.

* The Principal, St. Louis Institute for the Deaf and Blind, Madras

Other causes are: Maternal infection or drugs in early pregnancy, prematurity, perinatal illness, postnatal ocular infections, eye tumours and injuries, detachment of retina, cerebral tumour and deteriorating neurological condition.

According to the 1981 census there are about 0.479 million totally blind persons in India.

According to the 1991 census report there are about 19.2% ie., 2.12 lakhs of blind people in Tamilnadu.

Employment opportunities available for the blind persons

Educational Institutions	— College Lecturers, Teachers in Higher Secondary, Secondary Schools & Music Teachers etc.,
Watch Companies	— Attaching straps / Packing
Railways	— Typing/Peon cum Conductor. Announcement of Train arrivals + Departure.
Coach Factory	— Assembling parts of the Coaches
Motor Factories	— Assembling motor parts.
TV Companies	— Assembling TV parts.
Telephones	— Telephone operators.
Govt. Examination offices	— Packing and sealing
Banks	— Typing, Peon cum conductor Chair caning.
Transport Corporation	— Chair caning, Music orchestra.
Handloom units	— Weaving.
St. Louis Orchestra	— Conducts Musical Performance all over India.

Self-Employment Scheme — Musical performance, Chair caning, Weaving, Telephone operators, Lottery ticket selling.

In a recent Survey made by St. Louis Institute we have the following findings to share:— 47% of the Blind workers have said that they are accepted in the place of work. 20% felt that they were not accepted among the co-workers.

33% of the Blind workers felt that most of the co-workers sympathised with them, but they did not accept them.

25% of the Blind workers said that they enjoyed cordial relationships with co-workers, while 20% did not think so. 55% expressed having indifferent and at times hostile relationship with co-workers.

52% of Blind workers contended that they had congenial relationship with their supervisors or managers, on the whole. 25% said that they did not have congenial relationship with their supervisors/managers. 23% of them felt that the supervisors had contempt for them.

54% of Blind workers felt that they experienced a sense of achievement in their job. 26% expressed indifference.

61% of Blind workers wish more autonomy in their job. 26% did not claim for autonomy. 13% said they need more guidance from the authorities.

44% of the Blind employees felt that their pay is adequate, 30% responded that their pay is not adequate. 26% admitted that they have only a hand to mouth existence.

40% of the Blind employees reported that they have chances to use all their skills in the present employment. 44% of Blind employees reported otherwise 16% reported indifference.

54% Blind employees expressed that the skills and values learnt in the school are useful for them in their work. 46% did not agree. They desire to acquire skills in Computer application.

49% of Blind workers expressed satisfaction in their job. 32% expressed dissatisfaction and 19% expressed indifference.

‘What are the primary needs of the handicapped man—food? clothing? Shelter? Give him all these and luxuries too. But deny him the right to live, and you have killed his soul’ – K.V.

NIMBKAR.

Blind persons need acceptance, care, appreciation and recognition for their self growth and happiness. When these are denied to them they feel isolated and live a life of drudgery.

Blind persons are registered in the Special Employment Exchange for the Handicapped. They have to wait for many years to get an employment. Even when they do get employment, they face much opposition in their place of work.

Even highly educated blind persons working as Lecturers in Colleges feel that they are not well accepted in the college.

Self – image – Emotions – Crisis in life:– Samples of personal interviews:

R.C. is a born blind person. He had faith in God but he feels that God is not just to him. He is angry with anyone who contradicts him. He has contempt for the rich people. He works as a teacher.

V.K. is 40 years old. He lost his eyesight at the age of 7 due to smallpox. He could not accept the tragedy. He was angry with God, with himself and others at home. He is a graduate and works as a teacher. He is married to a normal woman and has one son. Married life is not happy because of suspicion.

A.V. is a 37 year old blind person. He was born blind because his father and mother were blood relations. A.V. could not accept his disability. He used to curse God and everybody

around. He would not obey his parents. He passed High school. He got a job in a factory. He married a normal woman and has two children. Married life was not happy. They are separated now.

Most of the Blind persons have uncertainties about their future. However, they do not seem to lose self-confidence altogether.

Blind persons have great expectations from the government. But they do not get much help from government. They face anxieties and frustrations. Some of them entertain guilt feelings that it was their sins that caused blindness.

Some of them feel that they are a burden to the family and society and wish to commit suicide.

Blind persons who have married blind persons seem to be happy in their married life. Blind persons who have married normal persons do not seem to be very happy, due to suspicions.

Special needs of the Blind persons:---

- * Acceptance in the family and in the society.
- * Special education.
- * Scholarships for higher education.
- * Mobility training.
- * Low-vision aids.
- * Vocational training.
- * Equal opportunities for employment.
- * Reservation of jobs for the disabled – blind persons.
- * Career guidance.
- * Sheltered workshops.
- * Medical care.
- * Social security coverage.

Conclusion:

The prophet Isaiah wrote:

‘Then the eyes of the Blind shall be opened,
And the ears of the deaf shall be unstopped
Then the lame shall leap like deer,
And the tongue of the dumb sing’— Isaiah 35:5-6

We shall strive to open the eyes of the blind and to open the ears of the deaf. We shall continue to help the lame to walk and the dumb to speak.

We who are able-bodied, shall pledge today, to rededicate ourselves for the cause of the differently-abled persons. We shall promise to utilise all our talents and abilities to train and rehabilitate the differently-abled persons in our society.

The Lord will certainly bless us abundantly, for whatever we do to the least of our brothers and sisters, we do it unto Him.



PHYSICAL HANDICAP

MS CLAIRE HEATON*

I want to tell you briefly about a journey - a journey to what is now called St. Mary's Polio Rehabilitation Centre, Khammam.

The centre was started in 1972 as a residential centre for polio handicapped children, the second such home set up by what was then known as CSI Council for Child Care. The first one, at Kancheepuram, was started in response to a felt need of the time. CSI medical workers in the Madras Diocese, meeting village children handicapped by polio, took them to hospitals like CMC, Vellore. The necessary surgical correction was done and calipers were given. But the people who referred them, to their surprise, later found the same children in the village in the same condition. They discovered that this was because of the inability of the families to follow up on the therapy already started resulting partly from lack of understanding by the parents and the family, and partly due to economic and social factors. So the concerned personnel felt that the answer would be to provide long-term accommodation where education and medical rehabilitation could go together. And so the first polio home came into being. In Homes providing long term accommodation, children are being educated and are given medical rehabilitation. The underlining policy upholds that, up to the time of attaining economic independence, the children should be the responsibility of the institution.

But in Khammam we now realise the limitation and the frustration caused by a programme that is purely long-term-residential. Many parents bring their children with special needs to the centre and we have nothing to offer them except a place on the waiting list. Thus we started what came to be known as the 'transit programme', for want of a better word. 'Transit' meant on the way from somewhere to somewhere.

* Superintendent, St. Mary's Polio Home, Khammam, A.P.

We run a daily out-patient programme where children with various locomotor disabilities are assessed and appropriate programmes are implemented. It might be caliper fitting or an exercise programme or corrective surgery. This caters to cerebral palsied and mentally disabled children as well. We provide accommodation where children and their parents could stay for a few days or a few weeks while the programme goes on. Here the parents learn what they are going to do at home.

Then you might say we have come back to the starting point—we started from a set-up with an out-patient programme and now we are coming back to another set-up with out-patient programmes. What is the difference then between this short-term programme and what is offered in any out-patient set up.

First of all we are geographically closer to where the children live. So it is easier for the parents to bring back the children for regular check-ups. Secondly, we are able to spend more time with parents, educating them about the importance of follow-up. We also have a limited postal follow-up. If the parents do not bring back the children after a certain period of time, we send a post card asking 'what happened? Why did you not come back for check-up'? This has its limitations because the parents don't always stay in the same place and the post cards sometimes come back to us. But it is a positive way of trying to bring back children for follow-up. We do have children on our lists who have been under our care for more than 10 years.

When the families are with us in the centre they and the children observe role-models, because they see children who have been under care for many years. And so the parents and children who are just on the start of the road to rehabilitation can see the progress of the children who have been under care for sometime. They understand the opportunities available to children who are said to be handicapped. As they watch children going to schools and as they see them playing games they are inspired and feel confident that their children could also do the same.

We sometimes hear people say about residential rehabilitation that we are shutting up our children in institutions. But we know that many handicapped children are shut up in their homes. And it is only by coming to the institutions that their doors are opened to the wider world. And I think that is what the institutions should try for—not to be opened doors where they come in and stay, but doors which open their lives to a better world.

The difference about our particular programme is that from this short-term programme, we can identify children whose handicap is severe, whose parents are not adequate to help, or who have no educational facilities in their village. Once they are identified, they can come into our long-term residential programme, if we think that is what they need.

Recently we were visited by a worker from a voluntary organisation in Mangal, —about 30 kms from our place. He said that he had a number of handicapped children in his village and asked if he could bring them to us. So I talked to him and together we decided to have an assessment camp. This was conducted by the staff of our centre with the help of that organisation known as CRISH. We conducted the camp in the Mangal headquarters office. We gave wide publicity through newspapers, and distribution of brochures. The Assistant Director of the 'Andhra Pradesh Vikalanga Cooperative Corporation', also attended. We wanted the government officials to at least be aware of what we are doing and what we wanted to do. Totally 148 children were seen of which 93 were polio handicapped. Out of those were children we thought were doing all right the way they were, or that we cannot do anything more for them. 30 children were given dates to come to the centre for calipers. 20 were assessed to be in need of surgery and were subsequently brought to our centre for assessment by the orthopaedic surgeon. A number of others were called to our centre for physiotherapy. To date 9 children have been operated and given calipers. The parents were also taught home-exercises to be done regularly. All the children from low-income groups were charged only the minimum for

treatment and appliances and the rest was met from our resources. This non-governmental organisation has developmental workers in villages in Mangal and many of the children come from those villages. They extend help and co-operation in the follow-up of the children's treatment.

This has been another step in the path towards reaching more children and opening our facilities not just to our children who have been with us for a long time but to children in the community.

Another programme which we have now in our centre is what we call 'Half Way House'. Have you noticed in hostels for normal children how the older children seem to wander where they like, take for granted all the services that are offered to them, and do not do the hostel duties which even the smaller children do? In our polio home, the situation is reverse. Once a child has passed class X or reaches the stage where we want to send him for some vocational training or in-service training, he goes to live in that Half Way House. From then on, it's that boy's own responsibility to look after himself. They have their own house, are given money once a week to do the purchasing, the cooking and the cleaning; even the planning of the food and the house set-up is all organised by them. By this we are training them in looking after themselves - an essential part of the rehabilitation programme. It is only a half-way house from there they go on to live in the community as independent members.

At the centre we are venturing out into newer areas:

Firstly, we have to care for children with locomotor disorders, other than polio. And if we are going to do that, we have to re-train our staff. That is our second priority. Thirdly, we want to do more for integrating the less handicapped into normal schools, so that we can move our children, who are doing well in our long-term programme, back to their villages to continue their education. If that is not possible we have the other option of putting them into hostels with other children who are handicapped, which is another form of

integration. As of now all our children go to a community school after the IIInd standard. Now we want the children who are less handicapped to live in hostels with other children without obvious handicaps.

We also thought a lot about introducing vocational training in our centre. But we realise from experience that most of the children when given a little guidance, help and counselling and are introduced to existing training institutions, can fit into a normal vocational training programme. This is also a part of the integration process that we are working on.

The question was asked here, in what way is the local congregation involved in any of the rehabilitation programmes? Are the programmes just done by the staff in the centre, helped by people who send the money from overseas? To a large extent this does seem to be what is happening. But in our centre we are making efforts to involve the congregation. Our children go to church on Sundays, and they attend the local schools. We also have a sponsorship - parent programme for our local people. And quite a number of people in our congregations and in the wider community have come forward to give regular monthly donations to support the work that we are doing. But this programme has to grow, for the people to feel that 'this is our centre and these are our children.'



INSTITUTIONAL CARE

MR. A. JEYABALAN*

I feel otherwise disabled, speaking on this topic because we have been hearing much about the other type of service delivery system, the Community Based Rehabilitation. CBR has been, in recent years, storming the whole world and shaking all of us.

Institutional care, on the other hand, is an age old system. Missionaries had developed institutional care even for 'normal' people, to rehabilitate those who were converted to Christianity. For people with disabilities, this system was initiated about two centuries ago. This included rehabilitation centres, homes for the disabled, institutions for the disabled and community extension services. And now the CBR.

The service delivery system took transformations from Social Reform Services to Social Welfare Services, from custodial care to permanent rehabilitation, from institutional care to community based rehabilitation services, and from special schools to integrated schools.

CCCYC* - a voluntary organisation working for the development of children who are poor, destitute, orphaned and disabled - operates through 400 institutions all over South India with projects for the so-called normal children. These include day-care centres for children with working mothers and around 39 projects for those who are disabled, 12 institutions for the intellectually disabled children housing 900 children, 12 institutions with 1000 children affected with poliomyelitis, 12 institutions for the hearing impaired children with 1600 occupants and several institutions for the cerebral palsied children housing 90 children. In all, it supports around 4000 children in South India.

* Churches' Council for Child & Youth Care, Bangalore.

The question often raised about Institutional care of children is 'do the institutions really have a role to play'. I would say *definitely*. Because in all the service delivery systems, even with all the new trends, we are not able to take care of many children who need our services - starting from children with mild disability to those with severe disability.

CBR may not be the only answer to cater to the needs of this population. If we study the magnitude of the problems of those with disability - 80 million people - we understand the enormity of the situation. So if we are able to systematically approach and implement the CBR programme, then 10% of the population with disability can be catered to at the community level, 20% at the tertiary level, and 10% at the institutional level. But the point is, we still require institutions to cater to the needs of these people. Most importantly, for the severely handicapped children, one cannot do without institutions which provide services by specially trained people.

I would conclude by saying institutional care still has an important place. For taking care of the disabled, institutional care system and the other delivery systems have necessarily to function as two sides of the coin, the latter to certainly include CBR.



PHYSICAL MEDICINE IN PRIMARY HEALTH CARE

DR. S.G. CHURCHIN BEN*

Addressing human health needs is a priority requirement of any society. Newer challenges in human life emerging day-by-day, world over, due to modernisation, changing life style, overcrowding, deprivation, dynamics of tour and travel, stress and strains of life, dehumanising socio-cultural practices, drug abuse, pollution and fast rate of development etc. have put in lot of constraints and limitations in effectively meeting the health needs of the people.

Very many of the common man's health needs are not attended to by the public health care delivery system, due to inadequacy of appropriate technology and know-how. The aim of this paper is to bring to light the benefits of Physical Medicine Services in alleviating and containing many of the common man's health needs which are not at present addressed by the existing health care delivery systems available through the primary health care services.

What is primary health care?

Primary health care can be defined as the sum total of all human efforts to deter and nullify all socio-cultural, environmental factors and dynamics of human relationship in our daily living pursuits, that have a definite negative influence on the health status of an individual, family and society.

In other words 'Primary Health Care is envisaged to enhance, improve or modify the living conditions of the people, family and individuals through curative, preventive and rehabilitative services'.

Primary health care policy of India :

—implemented on October 2nd 1952, based on the Bhore Committee Report, through Community Development Blocks in 5400 centers all over India.

* *Director, Medical Board, CSI South Kerala Diocese.*

The major aim was to make available Primary Health Care to villages, through the following services:

- * Medical care
- * Maternal & Child Care (& Family Welfare planning).
- * Control of communicable diseases
- * Environmental sanitation
- * School health
- * Health Education
- * Vital statistics

(Later National health care programmes were introduced during the successive plan periods. Example, Eradication/ Control programmes – Tuberculosis, Leprosy, Malaria, Venereal Diseases, correction of nutritional deficiencies, integrated into several health and welfare programmes like ICDS, National prevention of blindness programme.

All these refer to three basic activities:

- * Health promotion
- * Disease prevention
- * Treatment

Health to all, in all its dimensions, is a philosophy adopted by our Government whereby indigenous, traditional and Herbal methods were also promoted along with modern medicine, the latter made available mainly through Primary Health Centres, Taluk Hospitals and the District Hospitals (referral Hospitals).

Aim of Primary Health Care

To make available, efficient, most acceptable, uninterrupted health care and delivery services for basic health of individuals families and the whole population through judicious planning and implementation taking into account the needs, expectations and the available resources.

1. Daily living style and conditions of people should be taken into consideration while planning PHC.

2. PHC should adequately meet all the health needs.
3. Participation of people in policy making and implementation.
4. Health services should merge freely, and should co-ordinate with other developmental services.
5. Preventive, curative, rehabilitative and promotional services for the individual, family and the society.
6. Techniques and technology should be simple and easily adaptable for the common man.
7. Rely on available indigenous resources.
8. Making available trained personnel with appropriate skills.

The following aspects are not envisaged in the Primary Care concepts

1. Prolonged stay.
2. Use of sophisticated/complicated items of equipment and machinery for diagnosis or treatment.
3. Major Surgery.

Primary health care-Evolution – major land marks

1. Bhore Committee 1946 - 1952 October 2nd, recommended PH Centres in Community Development Blocks (Operationalisation of Concept.)

2. Mudaliar Committee 1961.

Mobile team of specialists to reach out to the villages, Development of Taluk, Hospitals - Referral services through District hospitals.

3. Kartar Singh Committee 1973.

Advised integration of all types of health workers whether looking after National or State Programmes into multi-purpose health workers.

4. Shrivastava Committee 1975.

Recommended that there should be a three tier system for effective implementation of primary health care. At the grass-roots level, the locally trained village health worker would represent the peripheral most basic unit for that purpose, and that the responsibility for health of the people is ultimately placed in their own hands. Provision is also made for institutionalised patient care and for the overall development of the village. Due emphasis is given to health education taking the local needs into account as well as the social setting.

What is Physical Medicine?

Physical Medicine is the treatment of patients using physical modalities. Electricity, water, heat, cold, paraffin, sand, mud, etc. are used as physical modalities with preventive, curative and rehabilitative values. As such they are harmless and do not unsettle the biochemical equilibrium of the body.

Exercises, massages, martial arts, 'thirummal,' 'pizhichil,' manipulation etc. are also physical modalities for promotion of health as well as for curative and preventive purposes.

Why integration with the PHC?

- Highly relevant to the present day needs of common man.
- Very cheap. Easily and readily available.
- Scientific, very safe.
- Simple, does not require elaborate equipment and training.
- Can be practised as a domestic programme.
- No need to visit consultants/Hospitals.
- Answers very many of the present day health problems that the existing Health Care Delivery System does not provide.
 - a. Pain relief.
 - b. Stress, strain, tension, anxiety relief.

- c. Functional ability, restoration following disease, injury, accident.
- d. Physical fitness improvement and assessment.
- e. Delaying degeneration.
- f. Enhanced life and productivity.
- g. Team work approach.

How is integration possible?

1. *Training and Education of personnel*—Capability building and skill development are essential to train enough personnel to practise this science.
2. *Infrastructure and equipment support*—Though not many items of equipment—are necessary, few therapeutic devices are absolutely essential for Health Care. Indigenous low-cost methods can easily be adopted.
3. *Needs and priorities*—One has to prioritise the needs. The requirement is for preventive, restorative or curative needs or for alleviating pain. Posture correction and physical fitness improvement etc. are some of the other needs.
4. *Delivery modes and means*—Most of the things can be done by the individual himself and can easily be taught and managed as a home programme. If it is not possible to do these by the individual self, help of an immediate attendant may be necessary. Positive health care principles and preventive medicine, such as recreational facilities or exercises can be introduced in daily routine.
5. *Community capability building*—Anyone can practice this art with little amount of knowledge making this a mass personnel development and capability building measure for positive health promotion and practice.

Tools of Physical Medicine

1. *Heat*—vasodilatation → increased circulation → More capillaries open up → enhanced phagocytosis and leukocytosis.

<i>Method</i>	Fomentation	Short wave
	Hot water bag	Microwave
	Steam inhalation	Ultrasound
	Heated Paraffin	Infra-red
	Hot Packs	(These are gadgets put to use in the institutions for the purpose)

- Caution*
1. Avoid in acute inflammation or trauma
 2. Obstructed venous and arterial circulation
 3. Malignancy
 4. Infants and Psychotics
 5. Loss of sensation, anaesthesia

2. *COLD* → Vasoconstriction → ↓ Blood flow → ↓ Metabolic activity → ↓ tissue temperature → ↓ spasm → induces relaxation → ↓ reduces inflammation → reduces pain.

- Method.*
1. ICE packs
 2. Ethyl chloride sprays
 3. Cold compresses

3. *WATER*—buoyancy of water provides gentle support without hindering movements. Physical activity can be carried out with lesser effort

- Method.*
- Water aerobics
 - Contrast bath
 - Whirlpool bath

4. *MASSAGE*

1. Improves venous, lymph return

2. Prevents capillary stasis

3. Improves circulation

4. Vasodilatation direct and reflux

5. Connective tissue menting - mechanical stretching and fibrosis containment.

6. Better recovery and removal of fatigue and delayed muscle soreness.

7. Muscular relaxation

8. Desensitisation of pain

Methods

Kneading

Friction

Vibration

Percussion

Contra-indication

Acute inflammation

Skin lesions

Malignancy

Circulatory diseases. Thrombosis

Concussion and trauma

5. *Exercise*

— Body has areas devoid of blood supply that needs physical activity to delay degeneration.

— Biofeed back principle - the more we work the more efficient one will be. Whenever we do not engage in enough physical activity our efficiency - cardiopulmonary fitness will come down.

Our muscles contain slow and fast muscle fibres. slow muscle fibres are always acting to maintain posture and shape of our body and this can be developed by physical activity. Fast fibres that determine speed of activity are destroyed by lack of physical activity resulting in disuse atrophy—lack of full range of movements result in shortening of muscles. Flexibility is proportional to the shortening of muscles. Proper posture is essential for mechanical advantage in gait and to minimise energy expenditure and to ward off joint diseases.

Exercise induced asthma

Exercise can precipitate broncho-spasm. But once an episode of spasm occurs it is followed by a refractory period during which any amount of work won't cause broncho-spasm. This method can be experimented with, to remain free of asthma on occasions when we want to be free.



FAMILY BASED TRAINING AND TREATMENT

(With special reference to intellectually disabled children)

MR. Y. SIMPSON*

Nambikai Nilayam is a centre for children with intellectual disability and gives training to children as well as their parents. The centre was started around 17 years ago. On Aug.8, 1978, five-year old Priya was brought to Nambikai Nilayam with moderate developmental retardation. Chief complaints about her were severe behavioural problems like destructiveness, and self injurious behaviour such as biting and head banging. She also depended on others for all self-help activities including eating. I still remember the first day she was brought to us. On interacting with the mother, I realised that she was apprehensive about continuing the training for 3 months. By the end of the day she told me that she was not happy about the training and wanted to stop the same day. In spite of repeated requests she refused to oblige and so finally I made a phone call to her husband. With a lot of persuasion from her husband she came back on the second day. It continued like that for about a month, with great difficulties on the mother's part. The questions which she raised were 'when will my child become all right?' 'Will she be normal at the end of three months / will it take some more time?' 'Can she go to a college,' 'what kind of medicines does she have to take?'.

After three months we told Priya's mother that the training at Nambikai Nilayam could be stopped and she could continue the training at home. She flatly refused and continued in Nambikai Nilayam for 9 years, at the end of which we were able to make the child self-reliant. At the time of discharge the child had no self-injurious behaviour. She was even skilled in a few activities like cooking, making plastic bags etc. This is Priya's story.

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The main reason why I narrated this story to you is to draw your attention to the question 'what made this mother continue for 9 years at Nambikai Nilayam'.

The trend of thought regarding mental disability has always been changing. Earlier it was thought that this was due to the sin of the parents. Because of that the person with disability was kept either in mental asylums or synagogues. Institutional care was stressed upon in later years. The present trend reveals 'wholistic approach' to disability – not only to the disabled person, but to the whole family.

To carry out an effective care process involving the family, it is essential that care personnel follow certain procedures or rules.

Being the parent of an intellectually disabled person is really a tough situation to be in. It is a traumatic experience for any parent to have a differently abled child. It adds lots of problems in the family, sometimes even in the family setting. Problems may arise among the siblings regarding scholastic performance and behavioural patterns. It could also create problems among other relatives in the family.

Therefore in the care of a child with intellectual disability it is important to consider the family as a whole, especially in the case of children whose parents are employed and who, therefore, find it difficult to come over to centres like ours to get the required help.

The child cannot be treated alone, if one is to give effective treatment. If we train only the child the parents would not be aware of the condition of their child, when he/she is ready for therapy at home. The parents would not then know how to handle various situations arising out of the caring process. In such situations it is extremely important to consider the family members as well. Any rehabilitative effort which takes into account only the child, becomes futile.

To involve the family maximally, the helper has to use innovative ways in order to help the handicapped and his/her

family realise that help is being given to family members as well as the person with the disability. While setting the scene for therapy they have to consider who the helper in the scene will be. It is not necessary that only the skilled professional or the care giver is the helper. Anyone - even a person who is closely related to the family - can act as a helper; somebody who has a genuine interest in the handicapped person.

Once the scene is set, the helper has to understand the family adaptation to the handicapped, because the disability has tremendous effect on the family. *e.g.* the husband-wife relationship. To understand the adaptation, the helper has to obtain a verbatim statement from the parents from which indications can be drawn about the attitude the parents have towards various aspects of the disability.

Most often parents perceive the problem in different ways at different stages. For example, as soon as the child is born they might think that the child has a particular 'problem'. But when the child grows the 'problem' might seem to take a different turn, and so the perception about the particular handicap also changes. Parents go through different emotions in this process - shock, denial and finally acceptance. The helper has to understand this and then act accordingly.

Once the adaptation of the family is explored, the next step is the helping process, the aim being helping the handicapped person enhance his/her self esteem, clearing doubts about his/her position, ensuring the well-being of the family, bringing about changes in attitudes and removing misconceptions.

With this aim in mind two models have been set-up. The first model is the 'Partnership Model'. This model is client oriented and is of four types:

- * individual parent, face-to-face. Here the parents are dealt with, individually and face to face with the care giver.

- * individual parent at distance-the parents are contacted through letters, telephone calls etc.,
- * parents, in group - face-to-face
- * parents in group - at distance

This model is being carried out effectively at Nambikai Nilayam. Every Tuesday we have a group meeting of parents where they interact with each other and share their feelings. During these sessions, experienced parents try to guide those who have just joined the centre.

The second model is the 'Expert Model'. This is in contrast to the partnership model. Here the helper has a dominant role in guiding the parents.

The first step in the process of helping includes various stages like rapport-building and relationship building between the helper and the client. The next step involves finding out the problems of the parents. This leads to the third stage which is called goal-setting. Depending on the goals set, plans are made to achieve the goals.

After the helping process is determined, efforts are made for its initiation. This involves essential counselling sessions, self-disclosure, immediacy etc. The meetings have to be set on the basis of information dissemination. On establishing a good rapport, parents willingly give more information regarding the child and their family. It is very important that the helper lets the parents know the truths about the handicap, right at the initial stage. But it should be conveyed in a way which ensures that they do not lose hope. Parents' decision to continue/discontinue the therapy will mainly depend on the way the helper interacts with them. If the first session is not effective, then there is a greater chance of the parents discontinuing the therapy.

At Nambikai Nilayam we go through three stages in breaking the news to the parents. First is the pre-counselling stage where the parents are made aware of various types of handicaps, hints are given about the possibility of the child

Having some disability and information is given about the nature of the handicap. The second stage includes finding out the 'assets and liabilities' of the child for treatment. Depending on this in the third stage, the parents are told about the disability and its implications. They will also be at this stage helped to ventilate their feelings. The helper has to be extremely supportive during these sessions.

In deciding on an appropriate model for the child, the parents are taken through a brainstorm session. Taking into account their suggestions, alternate methods/models are provided. This leads to the problem-solving stage where the parents are helped to set realistic goals for themselves.

Various plans of action are then implemented to achieve these goals. This is followed by an evaluation, carefully done to point out the efficacy of the plan. Depending on the success/failure of the programme new goals or methods are developed with the help of the parents and the helper.

Let me conclude by reiterating that unless we include the parents in the care system, all efforts to provide care can become futile, whatever be the handicap of the child.



VOCATIONAL REHABILITATION AMONG LEPROSY PATIENTS

DR. THOMAS M. V.*

Introduction

Reference has been made about the rapid decline both in the prevalence, as well as the incidence of leprosy in this country, which is indeed encouraging. It is a sad reckoning, however, that the social stigma attached to the disease does not appear to have changed at all. Leprosy continues to be the most stigmatised disease today and for that matter, even as compared to AIDS. Leprosy patients are still regarded as 'untouchables' or 'out-castes'; leprosy is considered as a 'poor man's disease'. A grave historic misunderstanding prevalent among the general public even today is that leprosy is an incurable disease. Another popular misconception is that it is hereditarily transmitted — that it is due to immoral life or due to unhygienic living conditions as in the ghettos and slums. Religion associates leprosy with a curse from God or sins during past life. All these factors contribute to making leprosy the most feared and dreaded of all diseases. Hence a victim of leprosy is most likely to be ostracised and debilitated; admittedly this brings into focus the great need for rehabilitation of those afflicted with leprosy. Undoubtedly, rehabilitation should be wholistic to cover the physical, mental, social, and vocational aspects.

Let me share with you some of our own experiences. We have an active control program in Gudiatham Taluk. In spite of our concerted efforts over the years, patients do not report to us. We have to make periodic family visits and conduct surveys to identify new cases. Once they are identified and put on treatment, they often fail to complete the treatment.

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Our national control efforts notwithstanding, leprosy is not diagnosed early or treated adequately. A recent survey points out that anti-leprosy treatment is available to only one out of every five persons suffering from leprosy.

Need for Vocational Rehabilitation

Among those with leprosy, and when we consider the need for vocational rehabilitation, experience tells us that the worst affected are the young persons including the students. A leprosy afflicted youth faces a very sinister problem, namely, lack of motivation.

This is mainly due to long periods of emotional and psychological trauma that he/she undergoes. The accompanying threat of stigma in society is yet another significant reason. This problem is seen particularly among those who have been residents of a leprosy colony or leprosy hospital for a long period. They tend to reflect an apathy towards life. They live for each day, not thinking of a tomorrow which evokes no interest and very genuinely no hope. And so, rejuvenating incentives and an interest in life is the first step towards rehabilitating young leprosy patients.

Now coming to vocational training efforts, there are two approaches, the formal and the non-formal. In the non-formal, we always look at the special needs of the patients-eg., the nature and extent of the deformities and the person's own background. We are all familiar with the clinical course of the disease - the insidious onset - often starting with an isolated patch, the associated loss of sensation leading to injuries and ulceration and resulting in deformities and mutilation. These are the persons not usually accepted in the society, with the result they resort to begging or stay in leprosy colonies. Often they represent the illiterate in the community. Job opportunities open to them are very limited. Some may with difficulty find employment in small village industries. A major step, would be to collect relevant data covering aspects such as, their individual potentials, background and previous vocation, where

applicable. Suitable vocational training is imparted based on such assessment. Usually they take up some crafts and thus make a living.

Coming to the formal vocational training, there have been certain developments. The Leprosy Mission in India started a vocational training centre in 1981 at Nasik, Maharashtra, for leprosy patients and their dependents. There are a few other vocational training centres mostly run by voluntary agencies, particularly on behalf of the Church - Salvation Army runs a training centre, at Nagercoil. Vocational training is offered by two voluntary agencies in Madras (Hope Rehabilitation Centre and Gabriel Rehabilitation Centre).

For the formal training courses, admission is restricted to those who have completed 10th Std. (Plus). The Vocational Training Centre in Nasik is today a full fledged centre, recognised by the Government of India and providing training in 8 trades. Leprosy Mission spends Rs. 10,000/- per year per student. On successful completion of the training, they are fully eligible to seek employment through employment exchanges. The Nasik centre provides training in the following areas:-

- Hand composing and proof reading
- Printing and machine operation
- Cutting and Tailoring
- Welding
- Stenography
- Secretarial Practice
- English Typing
- Motor Mechanic

So far 51 leprosy patients or their dependents have been chosen from the control area of Schieffelin Leprosy Research and Training Centre, Karigiri, and sent for training (see Table I & II for details).

Table 1 : Training undergone by Students from 1981-1995

S.No.	Name of the Trade	Total No. of candidates
1.	Hand composing	3
2.	Secretarial practice	11
3.	Motor mechanic	7
4.	Printing	11
5.	Welding	12
6.	Tailoring	7
Total		51

Table 2 : Nature of their employment after the training

S.No.	Nature of employment	Total No. of candidates
1.	Foreign service	1
2.	Government service	12
3.	Vol. organisation	19
4.	Self employment	12
5.	Unemployed	7
Total		51

An opinion survey conducted in 1993 by the Leprosy Mission revealed the following trends about the training:

1. Trainees are very happy about the quality of training they receive at the Vocational Training Centre, Nasik.
2. The training provides them, with confidence in themselves and in their potential to do the work. This is true specially of those who are self-employed.
3. Some of the cured patients pointed out that as they underwent training, they gradually forgot about their disease and disability and felt enriched, and also became conscious of their abilities.
4. Majority of them are of the opinion that when they produce visible and concrete results of their work (financial gains) the community accepts them and respects their dignity and right to livelihood.

REHABILITATION-ORGANISATIONAL ASPECTS AND POTENTIALS IN NETWORKING

*MRS. ALOKA GUHA

Introduction

Traditionally, Rehabilitation services for Disabled persons in India have been both urban-based as well as institution-based. It is estimated that in 40 years of rehabilitation services, only 2% of the disabled population in India have been reached, either by services or by information. 98% of persons with disability have had neither any knowledge of the existence of these services nor, of the benefits to be derived thereof.

The Need for CBR

From the mid-80s, planners and professionals had begun to accept the limitations of Institution Based Rehabilitation (or IBR) approach, when applied to a large, diverse, economically marginalised and predominantly rural population like India's. Different options for increasing coverage have been discussed at length and Community Based Rehabilitation or CBR appeared to be the most reach-effective, cost-effective and the most likely to achieve acceptance of disabled persons in their own communities.

Inclusion, or integration, is certainly the primary goal of all rehabilitation efforts on a global basis.

About SPASTN-IBR

The Spastics Society of Tamilnadu (or SPASTN) has been working in the field of rehabilitation from 1981. It operates through a continuum of services which includes Awareness creation, Prevention, Early detection, Early intervention, Special education, Physiotherapy, Pre-vocational/Vocational training, Job placement, Manpower development, Material development, Research, Making of Aids & Appliances, Advocacy, School integration etc.

**Director, Spastic Society of Tamilnadu*

Upto 1990, SPASTN's approach in this wide-ranging service delivery system was a purely institution-based one, through 3 multifunctional special education centres in the South Central and North Madras areas.

Organisational Change—Outreach:

In 1990, the expressed needs of our outstation parents from many other districts in Tamilnadu and from the neighbouring States of Andhra Pradesh, Madhya Pradesh and the Union Territory of Pondicherry prompted us to extend our services on an outreach basis to these places.

Community Based Rehabilitation:

This is the story of Project DARC, Disability Awareness and Rehabilitation in the Community, a CBR programme of the Spastics Society of Tamilnadu—a programme which is essentially a response to the felt and expressed needs of families of children with disabilities. It is also a programme which directly addresses the subject of networking which I have been asked to speak on.

DARC is a linkage model of CBR in early intervention, involving the community, the Integrated Child Development Scheme (ICDS) and the Primary Health Centres as its main partners, all linked together for the singular purpose of preventing, detecting and managing childhood disabilities within the community setting. DARC primarily serves the 0-6yrs age group, with special emphasis on the high risk newborn baby, i.e. the low birth weight baby, the premature baby, the birth asphyxiated baby and other babies who are at risk of acquiring disabilities or developmental delays. This is perhaps the only model in India where the Health and Welfare sectors have come together on a common platform to share resources and skills at the community level.

The house of DARC—Built with Multisectorial Pillars:

The house of DARC is built on 6 pillars, with the community as the foundation. Pillar one is Awareness creation, Pillar 2, is Screening and detection in hospitals, in balwadis, schools, and through camps. Pillar 3, is Early intervention on a multi-site basis, Pillar 4, is Training of GRWs and Pillar 5, is Referral chain. Pillar 6, is Cross-sectorial networking.

Some of the monthly Outreach or Extension services of SPASTN caught the imagination and the interest of the local communities and blossomed into full fledged Community Based Rehabilitation services for disabled children on a daily basis.

Sustainability—Networking is a need, not an option

This is perhaps the most crucial aspect of Project DARC the utilization of, and merging into, the facilities, programmes and schemes that *already* exist in the communities. This is where the ultimate question of sustainability of any CBR programme is tested. We made sure that we built it in from the earliest stages of Project DARC. Within one year of its inception, DARC has merged permanently into the existing infrastructure of the ICDS and the PHC and become part of the routine activities of the community.

Although DARC's primary involvement-group is the 0-6 yrs age group, it goes without saying that all ages, and all disabilities have been integrated into this CBR programme. Older children and adults have been involved through efforts in school integration, some through vocational training, others through job placement and yet a few others through aids and appliances like calipers, crutches, wheelchairs and tricycles which would enhance their mobility and independence. Community involvement, apart from the health and welfare workers, have been through disabled persons and their families, schools, religious organisations, fraternities like Mahila mandals and Youth clubs. Wherever they have taken over the responsibility for rehabilitation services, inclusion and integration efforts have been best served. This is especially so where disabled persons have taken the lead in rehabilitation.

In the ultimate analysis, SPASTN's role here is that of a catalyst, an agent of change. Whenever there has been a demand for services, SPASTN has responded with outreach services extended from the 3 urban centres. These outreach programmes have evolved in some instances into nodal CBR programmes. As each CBR programme strengthens, they in turn cap their achievement by starting outreach programmes of their own, which too will one day become nodal centres in their own right. Thus a rippling effect is created until first,

the whole district and later the whole state and neighbouring states are covered through rehabilitation services for, by, and of persons with disabilities.

This CBR model is more cost effective firstly, because it is supported by community resources, both in manpower and in material ways. Secondly, it utilizes and converges into infrastructure that which already exists in the community rather than set up new and expensive infrastructure. Their capacity has been strengthened to include and integrate issues, options, and services in rehabilitation.

Objectives/Activities of DARC

1. Prevention:

The objectives of DARC, which are concretised into actions, are very clear-it seeks first, to *prevent* disabling conditions, through greater public awareness and education. The emphasis in these direct contact awareness programmes apart from general preventive measures, is on the importance of nutrition and care in the prenatal and postnatal periods-a sort of 'do's and don'ts' of pregnancy. Simultaneously, knowledge about disability and the abilities of disabled persons is disseminated. Superstitions, myths and fears about disability are sought to be dispelled. This has helped to create greater acceptance of disabled persons and an understanding of the need for rehabilitation services. Equally important, we believe, is creating a more positive environment in the community in favour of disabled persons. So the parallel objective of Public Awareness Creation is to effect attitudinal changes within the communities. An entire cross-section of society is targeted--young adults in schools and colleges, mahila mandals, youth clubs, village and peri-urban community people, professionals, medical fraternity and personnel of different government and non-government organisations already working in the communities and so on.

A direct effort in Primary prevention is the provision of Paediatric Ambu Bags to the PHCs connected to SPASTN. The Artificial Manual Bagging Unit provides better management of birth asphyxia at the PHC premises itself and helps prevent adverse situations which could lead to cerebral palsy and

mental disabilities in many newborn babies. If not for this simple equipment these asphyxiated newborns have to be sent to the District Hospital, several hours away, by which time the brain may already be damaged.

2. Early Detection

The second objective of DARC is early detection, sometimes even *before* birth, through monitoring of high risk pregnancies at prenatal clinics in Government Hospitals. High risk pregnancies include those with attempted abortion, a history of still births, diabetes, hypertension etc. and of course those with a family history of disabilities.

The other major strategy for meeting the objective of early detection is, screening of newborn babies within 3/4 days of birth. This is implemented in 12 Primary Health Centres and one Referral Unit. In each of these health centres, nurses are trained simultaneously for sustaining SPASTN's early detection efforts. This non-medical newborn screening is more like a developmental surveillance where high risk newborns are detected, and monitored for 6 months. If sensory stimulation and proper positioning is provided at the neonatal stage, along with competence building efforts of parents, the developmental outcome of these babies is likely to be much better. This method can also be regarded as a form of secondary prevention.

Screening is continued beyond the newborn stage to the infant and early childhood stages, through the regular services of the PHCs, and through Health Camps.

3. Early Intervention

The third major objective of DARC is the early intervention services. This is through a holistic and eclectic intervention which includes physical therapy, communication therapy, special education, adolescent training and self-help skills. It is important to reiterate that the mother and child need to be seen as one unit.

Indeed, the partnership between parents and professionals is the corner-stone of any successful early intervention programme. In the rural and remote villages of India, where

transportation is as big a problem as paucity of trained professionals, parent-professional partnership forms a solid foundation for the child's development.

The problem of long distances and limited manpower has inspired multi-site service delivery options. The sites include the child's home, or a local patron's home, a room in a local school, or in the local church or even in the local PHC. Some of these intervention sites operate on a daily or weekly basis and some function as outreach programmes on a monthly basis. Early intervention must be seen here as a measure towards tertiary prevention.

4. Grassroot Workers Training – Networking Practice

The next major objective cum activity is perhaps the most imperative for the sustainability of the DARC, or for any CBR programmes for that matter. This concerns the transfer of knowledge to the community about disability and skills in rehabilitation. The curriculum is designed to include knowledge about all disabilities both for early detection and for early intervention, the focus, though, is on prevention. WHO describes CBR as a 'democratization of rehabilitation'. SPASTN's conscious efforts to demystify knowledge and skills in disability have helped a great deal in the democratization of rehabilitation and the empowerment of the local people. However, it is necessary to emphasize that this training recognizes the importance of a continuum of professional competence in CBR.

The Staff of DARC have been involved in this structured transfer of skills from the very beginning on a three-tier basis—

- To parents and to disabled people
- To the staff of ICDS, which includes
Anganwadi workers level I and II,
Supervisors and CDPOs (Child Development
Programme Officers)
- To the health workers – village health workers
(FMPWs) Community health nurses and Health
visitors.

Appropriate Paper Based Technology

An important part of the training is A.P.B.T. (Appropriate Paper Based Technology). This is a technique with which special furniture and therapy equipment can be made at no cost at all, from used card-board paper and flour. These strong and sturdy aids are particularly applicable for Indian conditions.

Health and welfare workers, as well as parents and disabled persons are encouraged to make use of this technology for their own homes and for their balwadis.

Infact the development of Low Cost Aids as well as the use of Consensus Technology is vital for the success and survival of any rural CBR programme in India. We have emulated David Werners' models to make parallel bars, prone boards, balance boards and hammocks, from used tyres and bamboo. This play cum therapy equipment can even be made by parents of children with disabilities. Such a play ground can be used by non-disabled children as well and it goes a long way in integrating children with disabilities.

Equipment which can be used as a corner seat and a standing tolerance frame can be made from mud and waste material in the child's home. It serves the same purpose as expensive wooden equipment but is more financially accessible to the families that we work with.

We try to incorporate in all our CBR programmes, the 4 principles of technology—appropriateness, accessibility, affordability and availability. Therefore, whenever possible local resources and local manpower are utilized.

Most disabled children, especially those in infancy and early childhood, benefit from orthotic devices. For the DARC project, the orthotists visit on a weekly basis assessing the individual child's specific needs and measurements. They devise innovate and indigenously made aids and appliances which on the one hand, enhance independence and prevent contracture and deformities on the other.

To facilitate awareness and training programmes, a great deal of training and awareness-creation material has been developed in consultation with the community workers. These include posters and screeners on early detection, brochures on prevention, booklets for parents and exhaustive manuals and video cassettes for community workers. The material is illustrated and the language used is simple Tamil.

Project DARC has generated a lot of data in the 2½ years that it has been operating as a full fledged CBR programme. The data reveals that the incidence of polio and leprosy is on the decline whereas the incidence of multiple disability is definitely on the increase. One of the reasons for this is that many high-risk newborns, who never survived earlier now survive traumatic newborn insults, due to better medical care. These fragile babies are the most vulnerable to brain damage and are likely to be in need of rehabilitation measures at a later date.

Whatever be the reason for this increase, we are now in a situation where the demand for special services, for children with multiple disabilities is on the rise. From the CBR approach, this group poses the greatest challenge. Yet on a national scale almost no CBR programme has addressed this group's needs in an ongoing, regular and large-scale manner.

Referral Services – Benefits of Networking

Any CBR programme usually addresses about 70% of all the needs of disabled persons, at the community level. The balance 30% would need to be referred elsewhere and this is one of the reasons why the 'linkage model' has proved to be effective, because of the strong partnerships forged between the Government programmes and the NGOs onward and cross-referral services for medical and vocational intervention is more easily facilitated.

While the concept of CBR is universally applicable, each CBR model must be uniquely tailored to suit the needs of individual communities. Since communities differ with regard to availability of resources, economic status and social attitudes appropriate adaptations and modifications are necessary. What

can be replicated is the broad model, which is what DARC, aspires to be. Universal in concept, but, specific in application.

ID-Interface on Disability-NGO Network

This effort is an attempt to link all the existing NGO efforts in every district in Tamilnadu. The aim is to build the capacity of these NGOs in early detection and early intervention. They can function as 'nodal centres' for their Districts as well. They in turn train existing village level workers in welfare and health so that ultimately every village in Tamilnadu is covered, in terms of disabled children in the range of 0-6 yrs.

Conclusion

In the final analysis there emerges the growing realisation that rehabilitation, as we have known it for the past 40 yrs, does not reach those most in need. In this light, there is a clear understanding that networking, linkages, and convergence of rehabilitation efforts not only has a great potential, but is the only possible strategy for a developing country.

David Haxton of UNICEF has said 'Nothing is costlier to a Nation, especially, a low-income country-than to allow a child to be exposed to the risk of physical or other impairment, to let it escalate into an irreversible disability and then to look for resources for rehabilitation that can never be adequate.'

It is worthwhile to repeat that in this context, Networking is not an option. It is an imperative.



OUR CALL TO BE HEALERS TODAY

FR. JOE MANNATH S.D.B*

Let me begin with a short reading from the gospel.

It is the passage about Jesus healing the blind man (Luke 18:35-43).

‘As Jesus approached Jericho, a blind man was sitting by the roadside, begging. When he heard the crowd going by, he asked what was happening. They told him, ‘Jesus of Nazareth is passing by. He called out, ‘Jesus, son of David, have mercy on me.’ Those who led the way rebuked him and told him to be quiet. But he shouted all the more, ‘son of David, have mercy on me.’ Jesus stopped and ordered the man to be brought to him. When he came near, Jesus asked him, ‘What do you want me to do for you?’ ‘Lord, I want to see,’ he replied. Jesus said to him ‘Receive your sight; your faith has healed you’. Immediately he received his sight and followed him, praising God. When all the people saw it, they also praised God.’

One of the big contrasts between the mythologies of other major religions and the Gospel is that, all the miracles of Jesus are miracles of healing and mercy. If you take Indian traditions or the myths of the Greek or Romans, we see that gods and goddesses use divine power to get engaged in human lives, to fight, to win battles, or to defeat enemies. In the gospels, power is equivalent to healing. Jesus never uses power to defeat an enemy or win an argument or to show that He is mightier than an opponent. His miracles are always miracles of mercy and healing. This is a remarkable difference between the gospel and the mythologies of other religions of the world. So much so that Jesus is called ‘The compassionate God’.

What does that mean? None of us has seen God, but each of us has his/her favorite images of God. Frankly, this is all we can have. Suppose each of us today were to use

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the word 'God', it is difficult to know what the other person has in mind when he/she uses the word. Now, this fantasy can be used to make us better people or transform us into incredibly evil human beings. And religion, including Christianity, has used it in both ways. Fr. Tony DeMello, the Indian Jesuit who has written many influential books and trained many people in spirituality, used to say. 'No one can know God, none of us know what God is like, none of us know God's will even when we claim to speak in God's name.' Frankly we don't know God and what God wants from us. There is no way for me to know if God wants me to be in this hall right now or say 'no' to the invitation and do some other work. Nobody can tell me this. As Fr. DeMello says, 'Since what we do is to create our own images of God, let us imagine God at least as the best among us, for we all tend to become like the God we worship.' If I worship a cruel God, I become cruel and justify my cruelty in God's name. If I worship a compassionate God, I tend to become more compassionate and make decisions which are more compassionate. Infact, the Bible itself has examples of this. The people who condemned and killed Jesus claimed to be highly religious. The claim to be religious does not make any of us good, godly or Christian.

The one thing that marks Christianity out is its compassionate presence. I have a small book which is called '*For the love of God*'. It is a collection of first person accounts of a number of people from different backgrounds—different religions, different professionals—on what God means to them, based on their experiences. One of the accounts is by Mother Teresa. She has a sentence which surprised me. She says that what matters is not religion, but compassion.

If you take the story of the blind man, he probably had no idea who Jesus was, or definitions of who Jesus is, what he stood for or the details of his preaching. He was a blind man and he must have heard from people that this man, Jesus from Nazareth, was preaching and he had healed some people. For the blind man, that was the only point that interested him.

It is unlikely that he was interested in the details of Jesus's teaching, or how it differed from some other prophet, or teacher. And this is typically the interest of most people in the Church or religion. They are only interested to see whether religion has something practical to give them for their difficult lives. This is what the average human being expects from religion and this is what people expect from our christian presence. Are we able to bring healing in a world where there is lot of pain? If we are able to walk the way as Jesus walked through this earth--without condemning people, without adding to their pain, taking upon himself the pain of humanity--then we become relevant.

Yet, none of us can erase pain or take it away. Some of us may be medical professionals, some of us may be in pastoral ministry and others in various professions. What the medical field can really offer is a little less pain and a little more time. You cannot erase death; you cannot cancel pain, you cannot promise even one human being an existence free of pain. That is not in our power. You cannot offer even your child a life without pain, however much you may wish it. Jesus did not remove all the sicknesses around Him in His time. Nor could he. I believe what each one of us is able to do is very limited. For example, if a doctor cures somebody, the patient may fall ill again the next day or the next month. I can give a person his lunch today, but I cannot guarantee him he will be never hungry again. That is not in my power. But a little amount of alleviation that we can bring, is frankly the only thing we can do; And that little is significant and that is what makes life worthwhile.

What we do for one another, and to one another, as human beings, in our day-to-day living is larger and more significant than what we do as professionals. Suppose one is a heart surgeon, another a psychotherapist and the third a priest. Before being a psychotherapist or a heart surgeon or a priest we are all human beings. And what we do in our interactions as human beings is far more significant and far more healing than what we offer professionally. The way I

behave with the bus conductor, or the cook or the boy who sells tomatoes—daily contacts which look small—decide whether I hurt or heal him. Through each of our seemingly small acts we either hurt or heal the other person.

Why do people go in for therapy or counselling? It is largely because, at significant moments in their lives, they have been hurt where they had expected love. A good part of therapy is to repair the damage done by significant 'others' in our relationships. Therapy itself does not heal. Only love heals. Therapy is only an additional advantage. Unless the person experiences genuine love in normal relationships, that person is not going to be made 'whole'.

All of us have the power to heal or to hurt. Carl Rogers, one of the most-quoted names in counselling, used to say that sitting in counselling groups, he was amazed at the power of ordinary human beings to bring healing, not in the least because of training in Psychology or counselling. He said often somebody in the group would be struggling with something and suddenly another person in the group with no professional training would say the right word which would help the struggling person. He has seen this happening so many times that he was convinced that the average human being has enormous resources for healing. If we feel empowered to use it, we could do an enormous amount of good. I believe, for instance, that the most significant thing we do today is not my talk here or you being part of this meeting officially. I believe that the most important thing today is how we treat each other today—during the coffee break or during the lunch break; whether you listen to a person with genuine interest, whether you speak a kind word or whether you speak well of the absentee or pull down her name. I believe these are the important things you will do in the coming twenty-four hours. So what takes place in these twenty-four hours will not come into the official proceedings of the meeting, but in this we act as Christians or we do not. Having Christian symbols, or quoting Jesus, or singing Christian songs, does not make any of us Christians. In fact, the murderers of Jesus

were experts at religiosity; it does not prove a thing. The way we treat each other in the so-called unnoticed events of life, either hurts or heals, and that is what makes us Christians—not the things we officially say or do in public.

Personally, I may take my diary and say I have a lecture at 10.00 a.m. today. But that is not what lends meaning to my day, as a Christian and as a human being. It is how genuinely I love or care for people in ordinary events of life. That is what makes me a Christian or does not make me one.

We may help each other to discover our deep and strong capacity for healing or our deep and strong capacity to hurt. Part of our call to bring healing is to be aware also of the deep ways in which we can hurt people. We all carry a capacity for deep cruelty. If we think we do not, then we are fooling ourselves. And precisely those relationships where we can heal each other and bring love—relationship involving spouses, parents, clergymen, professionals—are also relationships in which we can cause pain. And this is why Christian compassion needs necessarily an element of repentance and reconciliation. None of us is God, or pure love incarnate. We hurt, we need healing, we need to apologize and start again. We need to admit that in the place of love, we have spread something else. This honesty is the best thing we can bring to each other.

In the story of the blind man, we see Jesus' well-intentioned disciples trying to keep this nuisance of a man, away from their teacher, saying that teacher has got more important things to do. 'Who are you to come and spoil the whole plan?' 'You are a beggar on the road.' This is often what we also do in our settings, We think important religious leaders should have time for 'important' guests and 'important' functions and to listen to a weaker person is not his job. In any society, there is a majority of 'statistically insignificant' people and others who are considered 'important'. This was the case in Jesus' time too. But we know that Jesus came among us, not to walk around with the definition of God, but to show

incredible compassion to persons who were considered non-persons in society. This is what showed us that He is God. And I think this should be the distinguishing mark of any christian setting or person.

One day in a school in Madras, a Sister Principal was told by some teachers, 'Sister, you must send for the watchman at the gate because he lets beggars and lepers come in. It does not look nice for the school.' She thought about it for sometime and then she said, 'No. This will not be a Christian school if only well-dressed people and those who have money are allowed to come in. So I will not reprimand the watchman.' I believe finally this is what it means to be a Christian. Do we use our buildings and our facilities to keep the poor out, or to welcome them ? We can do both. We can use the very Church structures to welcome those who are in need or to keep them out, for deep down our values may not be there of Jesus, but there of power structures. The Church, like any other institution that is human, tends to be inward-looking and power-conscious. In any given organisation, and in churches too, the main concern may turn out to be not service, but power. Historically, even competition among Churches is not based on how to be faithful to Jesus but how to have more power. This is a sad human reality.

What is our Christian presence if we only feed the overfed? What is our Christian presence if we neglect the poor, the dirty, the unwanted, the looked-down upon, those whose name nobody bothers to find out and who are not given as much access to authority as an influential person, the so-called VIPs? In this, I believe, today we should support those movements and organisations that take up the cause of the poor and the marginalised, irrespective of their religious or other affiliations.

While we should draw inspiration from the gospel, the gospels are not blue-prints for detailed, concerted public action today. We do not live at the time of the Roman Empire; we live in a democracy. Part of our christian commission to the healing ministry of compassion is responsible social and political

activity. God will not heal any of us miraculously. The majority who are deprived of their rights today have as much right to our medical service, health, food, security, education. A small minority like us is by no means in a position to do even a small fraction of what is needed. But we are an educated minority. We have access to education ourselves and we have access to many others through our educational institutions and through our hospitals. So an important part of our Christian task is, to raise the consciousness of our fellow citizens, of whatever religion, about the rights of people to be treated as human beings in the area of healing which many do not enjoy.

In the story, this beggar has access to Jesus. This is not the case with many other 'beggars'. There has to be a particular setting for the people to receive healing. Gustavo Gutierrez, the famous liberation theologian, asked us once during a lecture, 'Have you heard of Arch-bishop Romero (who was killed while saying Mass ? Everybody said yes. Then he said, 'In that shoot out several farmers were killed. Does any of you know their names'? Nobody did. His comment: 'This is what I mean. An arch-bishop's life matters. A poor farmer's life or death does not'.

We are a living Christian presence if what happens to the so-called non-persons matters something to us. Jesus had time and attention for this insignificant man on the roadside whom he could have ignored very well, and whom his followers were trying to ignore.

There are many others like the blind man who are calling to us for attention. There are many who are voiceless. Our ministry involves not only our individual presence that is compassionate, but also our efforts to bring in an awareness about the rights of people to healing, to medical service, to insurance policies and the likes. To be educated involves a responsibility. If we do not commit ourselves to what we believe, much of our prayer and faith is an escape.

I end by reminding you and me that the heart of Christian ministry is compassion. This is how Jesus walked the earth;

this is how we are called to walk. Beyond and before our so-called professions we are sons and daughters of God. We are human beings with great potential to hurt or to heal. How we do this in our very normal settings would show us whether we are Christians or not.

Let us end with a small prayer.

Lord, we pray that we may not only use your name, but live as you lived, sharing our resources and power to bring compassion and healing to those around us. May we never use power to lord over people, cut ourselves off from the poor or ignore those who need us most. This prayer we make through Jesus Christ our Lord. Amen.



REFLECTIONS ON THE SECOND DAY'S PROCEEDINGS

DR. M.C. MATHEW*

Yesterday evening my son told me something about conferences and conventions. He said, 'in a conference you get food to eat, you have a good place to stay, you get to sleep during sessions, and chit chat during the night.' I thought that was a good description for an 11 year old, to give about conferences! But I told him that ours was a different type of conference.

I am sure that as we have come to the beginning of the third day, we all feel that it has been worthwhile to be here, that it has been an exercise of interacting together as a community, to understand some issues that are of common interest to all of us.

The theme that emerged yesterday was the theme of *journey*. We heard this referred to, by many speakers, that we are on a journey. Let me try to reflect on that from three different dimensions.

First, the journey into ourselves. Life is a journey, from the womb to the tomb. It is a journey because it has an origin, a course, and a destiny. And because it is a special journey when we are here on this earth, we heard from atleast two of our speakers yesterday that there exists this dimension of an inward journey. The origin of our inward journey corresponds to the time we responded to God's call in our lives. Each of us has had a beginning in terms of responding to what we are today. The course of our journey is our vocation. Each of us is involved in something that to us, is very valuable and which makes our lives worthwhile to live. Our course is like a journey along the mountain path, which

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in spite of its steepness, is an onward journey. There are peaks and valleys in our lives-both pleasant and unpleasant experiences. Sometimes we feel like Elijah, waiting at the brook, while the brook is drying up. And yet, we are led out of the brook to a still better place to find ourselves nourished and cared for.

This journey of life in its course, brings to us, very many rich experiences. We were reminded yesterday that it was like a marathon running race. All of us are winners in that race. That emphasis, that all of us are winners, whether we run fast or slow, helps us to realise that the course in the journey of our lives is richly blessed by the companionship of the one who has called us.

The destiny of our journey is unknown to us. Recently I heard a wife speak about her husband 'I go where he leads me and I eat what he gives me'. To me, that was a beautiful expression of the unconditional trust that she has in her husband. In one sense, this speaks to us something about the journey of life. We know nothing about what will happen to us the next moment or the days thereafter. And yet, we are reminded that He who holds the future keeps us as the apple of His eye.

Henry Naoman, a very famous author and writer has something very interesting to say about his journey. He was an outstanding scholar and spent several years in academic pursuits. But out of some inward restlessness he decided to take a break and went to live with people who have special needs, at the Day Break Community in Toronto, Canada. This community is a group of people who have different disabilities and handicaps and are part of the international large community. Having gone to live there, Henry Naoman had this to say 'in spite of all the attractions of my university life and career, I have had an empty feeling within myself. And now having come to live among the poor and fragile people, I am learning lessons of love, simplicity and poverty of spirit'.

For Henry Naoman, it was an inner journey of discovery and learning. It was a journey of emptying, journey into the likeness of Jesus who emptied Himself of everything, except love. That seems to be the destiny of our lives. In this journey into ourselves, we have an origin, a course, a destiny. A destiny to be filled with this knowledge of God's love.

The second dimension I want to refer to about the journey, is the journey into the world of realities. We were reminded yesterday by several speakers, about the needs of those with hearing impairment, visual impairment, those suffering from leprosy, cerebral palsy, intellectual disability, poliomyelitis and those children in residential homes and in various hostels. We were reminded about the complexities and situations of stress and need of such people living in various circumstances of need. The needs were represented to us vividly, movingly and very convincingly. These have been in existence from the time of Jesus, and from historic times. These needs will continue to exist in the future as well.

What, then is our response to this need, is a question worth looking at. Are we just responding to the *need* or, are we responding to *people* who have needs ? This is a very important distinction. It is good to have a christian perspective on this as we look at this searching question. The needs can be met by various programmes. So we may have community-based rehabilitation programmes or we may have residential programmes or we may have big institutions to meet the needs of people having various kinds of needs. We may have professionals who are trained in various disciplines to respond to these needs. We may have imposing buildings, attractive structures or very gratifying models to respond to these needs. But we also know that some of these can be selfish attempts to respond to the deep secret ego of each one of us who is involved in delivering services to those who are in need—sometimes even exploiting their suffering to acquire importance for ourselves, to foster our position and to acquire authority and power. That is the unfortunate outcome when our approach is need-based.

What then, is people-based approach ? How do we respond to people who have needs ? This calls for a different orientation. Jesus Himself reminded us, 'I have come, that you might have life, and have it abundantly'. Upbuilding and transforming people who are differently abled is our call, not just being providers of their needs. To uphold people, calls for a different outlook. There is a famous saying 'go to people, begin with what they have, grow with what they have, and when the task is accomplished, let us say, they have accomplished it themselves'. John the Baptist said, 'He must increase, I must decrease'. Infact 'upbuilding' is at the heart of involvement, —that others must prosper, and we, the providers must become less important. Let those people with different needs, acquire skills and grow to do things on their own so that we are no more needed. Jesus Himself did this. While being with 5000 people who were hungry, He turned to his disciples and said, 'you give them something to eat'. Jesus was not the main actor in the drama of that miracle of providing for the needs of the 5000. It was the disciples. Our involvement to respond to the needs of people must be people-based.

The third dimension I want to mention, is the journey into the future. The future has many promises. We are happy that the incidence of leprosy is under decline. We are happy that poliomyelitis may be eradicated as it has been in 145 countries in the world. We have better community health services, because of which many preventable diseases—diseases leading to disability—will be on the decline. But we were also reminded yesterday of the new scenario that might emerge. A large section of the senior citizens perhaps 20% of the population, and a large number of people who suffer because of AIDS will now need more of our care. What about the increasing number of broken homes and broken marriages? What about health and developmental needs of women? We have thousands of children in every city of the country who are engaged in child labour. We have a few million children who are on the streets, engaged in anti-social behaviour. We

have a teenage population which is exposed to the menace of affluence and materialism and consumerism. So the future scenario looks to be different from what we are used to. And here comes the call for us, to respond to this.

Most of us who are used to conventional approaches would think that high-technology would provide the answer to this need. Many hospitals are engaged in acquiring more and more technological facilities. And so an appendicectomy which used to cost around Rs. 1,500 in a small hospital, now costs Rs. 25,000. In a corporate hospital, because appendicectomy is done by a laparoscope, it costs about Rs. 65,000. Technology is good, but does it meet the needs of the poor? The new economic policy has unfolded yet another mythology before us. We were told it will meet the needs of the poor. But who are actually gaining from it? Those who are in the upper class of society, definitely. They get better cars, better televisions, better resorts to go to during holidays; they have better facilities of saving. The poor again get marginalised. Liberalisation is a logo that the politicians use to silence us and to fool us.

We are about to face 'donor fatigue'. There are about 100,000 voluntary organisations in this country. At least 70,000 of them are begging for help from various donor agencies. But donor agencies continue to nourish and support those whose credibility is high and whose profile is very acceptable to the community. We now see that with the economic recession going on in Europe and other countries, donor agencies are finding it difficult to respond to all the needs.

So if high technology is not the answer, if new economic policy is not the answer, if there is 'donor fatigue', where do we turn to, as we look at the future realities? May I repeat, in answer, what has been echoed during the past two days in this room? The *congregation* is in the heart of the ministry of our Lord Jesus Christ. It is the congregation which is the treasure-house of resources. It is to the congregation that we

shall return, to meet the needs of people. *The local congregation is at the very heart of the mission of the Lord Jesus.*

I want to conclude therefore, by saying, if we want to stress on one call that has been emerging here during the last few days, it is this, that let us return from this place to activate our congregations, to be involved in the mission of the Lord Jesus. A journey into ourselves, a journey into the world of realities and a journey into the future. And may this journey bring to us a new life in our congregations.



EDUCATION AND TRAINING OF THE DIFFERENTLY ABLED

***PROF. P. JAYACHANDRAN**

At the outset, I would like to place on record, my appreciation for the Church of South India, because in Tamilnadu, it runs the majority of organisations which look after the needs of children with intellectual needs.

A look at the life of Jesus Christ here on earth, would reveal what kind of person one should be, and how one should live one's life. Each of us need to consider whether we are able to fulfill the demands He makes of us—at least a few, if not all. In every encounter that Jesus has in the Bible, he is trying to tell us 'you need to understand yourself well. Each of you is destined to do something and so involve yourself in that'.

To me, the most powerful passage in the Bible is that of Jesus healing the blind person. The people asked him, 'Is he blind because of his sins or his parents' sins?' Jesus's answer is very clear—he is blind in order to bring glory to God. I have had discussions on this with various religious leaders and everybody is of the opinion that some children are differently abled because, in their way, they should bring glory to God. If that is so, then we who work for these children can be very happy doing that.

I was asked once, 'why did you choose this field for your career?' I replied. 'I believe that I, as everybody else involved in this field, have been selected by God and are given the wisdom to do this work'.

Let me share with you some thoughts on children with intellectual needs, based on my work and experience.

In 1968, when I decided to involve myself in the field of disability, I was selected to join the field of mental disabilities. I told the selectors 'I do not know anything much

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about it, so why give me this field'? They told me, 'you are the best among the worst, so we have selected you'.

Eventhough I was a qualified psychologist, I was never introduced to the field of intellectual disability. The first glimpse came only when I was doing my Master's level programme. Medical knowledge imparted to professionals about this disability, is negligible. The time spent by medical students in exploring the field of mental disability is very little (13 minutes to 3 hours during the entire course, says a survey done for UNICEF) and they are therefore inadequate to deal with these children. This is a tragedy of our country.

When I entered the field, there were-only a few homes for children with mental disability, in Tamilnadu—one for orphaned children with intellectual needs —Dr. Boaz Memorial Hospital which had about 6 children. Today, to my knowledge, there are around 130 centres in Tamilnadu which serve around 3000-4000 children and adults. But every centre in the country, faces primary problems of trained human resource and finance. A centre with trained staff and adequate facilities can open up a world of possibilities for children with special needs.

Perhaps the most important point to keep in mind while training the differently abled, is that each individual needs an academic curriculum suitable to him/her depending on his/her age, intelligence level and the type of handicap. Infact a group of persons referred to as having intellectual needs is infact, a heterogeneous group—their age is different, their level of intelligence is not the same, their adaptive behaviour varies, their associative conditions are different and so on. For example, the training given to a child with down syndrome is very different from that given to a spastic child. In the latter, the muscles are very stiff, while in the former, muscles are extremely flexible. And so their training varies. One of them may even have an additional handicap or may be, is epileptic. The training scheme, again, varies accordingly.

Therefore, a trainer does not deal with a group of people who are differently abled, but he trains each individual in the group. Accordingly the strategy is different and the task becomes challenging. A particular programme which works

for a child may not work for another child, –may not even work for the same child at a different time. So the teacher needs to have a clear understanding of the child, his/her potential, level of motivation etc, while planning out a suitable strategy. The curriculum then becomes unique to every individual.

If this is to be possible, a team of inter-disciplinary professionals is imperative, because it is not practical and competent for one person / a small group of professionals to look into the different aspects concerning every single child. There needs to be a strategy where all resources can effectively be pooled together and shared with one another.

In what areas can one train children with special needs? For a child with hearing impairment a hearing aid can help normalise her hearing function, for a child with locomotor needs, a wheel chair can be of great help. This is so because her intelligent level is normal. But, for a child with intellectual needs, her low Intelligent Quotient does not allow normalisation of all functions. A child with intellectual needs perhaps may be able to sing well. This is because one of her faculties is well-developed; yet she is not on par with others.

So a person with intellectual needs has to be trained according to his/her abilities. For maximum efforts, the child's needs are classified into gross motor functions, fine motor functions, receptive language, expressive language, grooming, social interaction etc. When the child is below 6 years, training efforts are concentrated on the 'fine' motor area of the brain. Unless that area is developed, the child will not be able to carry out even basic functions like holding a pencil. During this age, if she is not trained in toileting, she cannot be prepared for community life.

During 6-12 years of age, concentration is on personal, social and academic skills. Training during this time tries to make sure that her learning is functional. For example, I may be able to teach a child with intellectual needs to count up to 100. But if I ask her to get me two mangoes from a basket, she will not be able to. Instead, if I teach her numbers and then show her how to functionally apply it in her day-to-day

activities, the learning becomes useful. And then if I give her Rs. 10 she may be able to buy a loaf of bread for Rs. 7.50 and return to me Rs. 2.50. That is the kind of functional academics adapted for children of this age group.

Most importantly, training given to children with special needs should help them lead decent lives. One is not trying to make scholars out of them. Not at all. The training is to be aimed at practical and essential functions of life, so that they need not depend on others always. If they see fire, they should be able to recognise danger and get away from it as fast as possible. If they need to send money, they should be able to fill up a money order form, sign it and send it to the right address. A child with special needs may be taught the map of America or the position of the equator, but if she is not taught how to identify a bus she needs to board, then the teaching is of no use. Similarly, children with special needs need to be trained in community-oriented activities, recreational activities etc.

It is important to involve the community as well, in carrying out the training programmes. It could be of tremendous assistance if the right sources in the community are tapped at the right time. Let me illustrate with an example. I wanted to train the children of our school in shopping for essential items. So I approached a super-market in the city and asked for the shop owner's permission to take the children over during that time of the day when their business was lean. He readily agreed and now we take our children to that shop once a week. The children come with a shopping list as well as enough money from parents and they do the shopping themselves.

The training of children with special needs can be compared to what happens in an industrial production unit, where the 'raw material' is subjected to strict processing, so that the finished product is of acceptable quality conforming to the expected standard. In the case of our training centres, I feel that accountability is something which we often lack. The teachers in the special schools are like the 'skilled workers', in a production unit—the raw material is the child with special

needs. *One has to assess the special needs as well as the potentials of each child and set targets that are achievable. There should be documentation that the progress made by each child can be measured, monitored. A child who goes through a special school comes out after his/her training, less dependent and more in control of himself/herself. For that they need additional help and support. How much we help them reflects on what they become.

**Prof. Jayachandran had the unique experience of evolving a 'training model' for the children with intellectual needs, as early as 1976, for the State of Minnesota, USA.*



ETHICAL ISSUES IN REHABILITATION OF THE DIFFERENTLY ABLED

*THOMAS P. KALAM

Ethics deals with values and norms. Values always contribute to human self-realization and happiness. Norms are the concrete ways of translating values into one's life in a given context.

Ethics of rehabilitation of the differently abled is a systematic thinking on the *values* that are at stake in this area, and formulation of *norms* to protect these values.

The values involved here affect the self-realization, happiness, of not only the differently abled, but also of the people who care for them. The ethical norms that we develop to protect these precious values must enable us to grow and celebrate life along with the differently abled.

The core value: Sanctity of life is not related to the abilities of a person

This ethical principle is eloquently explained in the parable of the talents (Matt, 25 : 14ff). The three servants in this parable are differently abled. The great thing is that the master does not expect the servant who received two talents or one talent to multiply them into ten like the servant who received five. He expects from each one according to the talents he received. In this reckoning, 2 can be more than 8. For example X receives 5 talents, and Y 1 talent. Y doubles what he received into two. X half-heartedly increases the 5 talents into 8. In His Kingdom, the two which Y has is much more in value than the 8 that X has, because Y doubled what he received, whereas X half-heartedly increased 5 into 8. According to the justice of the Kingdom, the one who started work at six in the morning and the one who was invited to begin work at three in the afternoon will be paid the same wage, provided each one was *faithful* to what was entrusted to him/her.

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Sanctity of life does not depend on sanity or stamina

The fact that among saints there are a lot of neurotics need not scandalize or surprise us. They are saints not because they are mental heavy-weights, but because they responded to God's call whole-heartedly.

Mother Teresa once said: 'My God is not asking me to be successful; He is only asking me to be faithful.'

Those with special needs can be included among the category of saints known as 'holy innocents.'

The basis of ethics of rehabilitation of the differently abled is the belief in the unrepeatable value of each individual human life, and in the transcendent dignity of those who are called into existence however differently abled they are.

The best way to manifest this belief is to exercise it with regard to the most marginalized of human beings. That must be the reason why the neglected, the disadvantaged, the poor, the suffering and sick were the ones to whom Jesus specially brought, in words and actions, the proclamation of the Good News of God's kingdom breaking into human history.

Some Norms arising from the unique dignity of the differently abled

1. The first norm, which is derived from this basic value, is that the differently abled person (whether the disability is the result of a congenital handicap, chronic illness or accident, or from mental or physical deficiency, and irrespective of the severity of the disability) is a fully human subject, with the corresponding innate, sacred and inviolable rights.

2. In the differently abled person there is reflected in a mysterious way the image of and likeness with God. Christ Himself mystically identified Himself with the suffering neighbour. He accepts everything done for the least of His brethren as done to him (Matt. 25:31-46). Christian approach to the differently abled is motivated by this vision.

3. Christians recognize the fact that a human being possesses a unique dignity and an independent value, from

the moment of conception and in every stage of development, whatever his or her physical or mental condition.

4. Indeed, on reflection, one may say that a disabled person, with the limitations and sufferings that he/she suffers in body and faculties, emphasizes the mystery of the human being, with all its dignity and nobility. When we see a differently abled person, we see the hidden frontiers of human existence, and we are impelled to approach this mystery with respect and love.

Nurturing non-interference: the basis of care of the differently abled

The greatest temptation of human beings is to interfere with everything and everybody in order to fashion them according to their own standards. St. Paul said: 'My little children, for whom I am again in the pain of childbirth until Christ is formed in you' (Gal. 4:19). The problem seems to be that even now people are in labour pain, not until Christ is formed in you, but until 'I' be formed in you.

The problem in the care of the differently abled comes from the fact that the so-called 'normal world' tries to fashion the differently abled according to their own image. A Taoist approach may be an antidote to this attitude of hegemony of the 'normal' over the differently abled.

In Taoism each person has his/her own *Tao*.

'Tao' means the way, the Path, and by extension- the absolute reality- the origin and unity of all beings. Everything has its way, the universe as a whole has its way. The way of each individual is its nature, its manner, its internal law of development, its wholeness. That is the Tao of each thing. All elements spring from the same source, unfold their potentialities through life, and return to their roots, having fulfilled their destiny. That is the Path, the Tao of the world.

If 'all under heaven has the Way,' what would be the right human action? Undoubtedly, it would be to scrutinize that way and to follow the same trace, without trying to

impose one's narrow view, one's own will, to deviate things from their natural course, for one's benefit. This attitude is called Wu-Wei.

The most characteristic of Taoism's feature is Wu-Wei. This term is often translated as non-action, or creative quietitude. It can be better rendered as 'Don't force it' (Alan Watts) or 'non interference' (Lin Yutang.)

'To interfere with the life of things, means to harm both them and oneself. But to rest means to effect, to purify one's own soul means to purify the world, to collect oneself means to renew creation. He who imposes himself, has the small manifest might; he who does not impose himself has the great, secret might. He who 'does nothing', effects. He who is in complete harmony is surrounded by the receiving love of the world. This action, the non-action stands in harmony with the nature and destiny with all things, with Tao' (Martin Buber, *Pointing the Way*).

This was what Carl Rogers was referring to when he wrote: 'When I really hear someone, it is like listening to the music of the spheres, because beyond the immediate message of the person, no matter what that might be, there is the universal, the general. Hidden in all of the personal communications which I really hear, there seem to be orderly psychological laws, aspects of awesome order in which we find the universe as a whole.' (Rogers, *Freedom to learn*).

The principal task of the care giver of the differently abled is to discover the point where the person hurts, at what point of growth he/she is, where come all misfortunes in his/her life. This is done by listening to the differently abled with profound attention, which is often described as 'active listening'. If the care giver's mind is full of theories, of prejudices or some superiority complex, thinking that he/she is the master, he/she knows what normality is all about, or that he/she is cleverer, more learned and experienced, this listening may never take place.

The anti-psychiatry school of psychotherapy (Laing, Szaz, Cooper) emphasizes this point even with regard to schizophrenic and other psychotic patients. If we listen without prejudice, we can understand them.

Andre Auw, in his book *Gentle Roads to Survival*, gives us description of this lack of listening. He was counselling a man who had visual needs. At the end of one session, he offered to accompany his client across the street. He took the man's arm. But the man stopped him: 'Let me tell you how to help a blind person across the street. First of all, don't take me by the arm. You are going to push me or pull me, and I may lose my balance. Also, I will end up at the place you think I should be. Instead, I would like you to offer me your arm. I will take as much or as little of your assistance as I need, and I will get safely to the place I want to be.'

Carl Rogers once confessed: 'Every significant thing that I know about people, I have learned from people, by listening to them, by trying to feel my way inside of their lives, to understand them from the inside, without judging or evaluating them, just trying to sense as accurately as I can, what it is like to be that person, living his life at this moment of time.' (Rogers, *Sharing something of yourself*). It is then that the care giver coincides with the flow of energy in the differently abled, with the laws of psychological connection between passions, feelings, emotions...and with the dark side of inhibition, fear, powerlessness, and disability... .

When you are nothing, then you can reflect everything. In John the Baptist's words: 'He must increase, but I must decrease' (John 3:30).

Martin Buber's description of the Taoist man can form the basis of ethics of rehabilitation of the differently abled: 'He does not stand opposite the creature, but embraces it. Therefore his love is wholly free and unlimited, it does not depend upon the conduct of men. It is the unconditional love...He does not interfere in the life of beings, he does not impose himself on them, but he helps all beings to their

freedom; through his unity, he leads them to unity, he liberates their nature and their destiny, he releases Tao in them.'

'To accept oneself and not to dream to be other than who you are. Here is a down-to-earth attitude, respectful of nature and its realization: What is long is not considered as an excess, and what is short is not regarded as wanting. For duck's legs, although short, cannot be lengthened without dismay to the duck and a crane's legs, though long, cannot be shortened without misery to the crane. That what is long in nature must not be cut off, and that which is short, must not be lengthened' (The Wisdom of Lao Tse).

The consequence of acceptance is that one is content of what one has: 'There is no greater curse than the lack of contentment. No greater sin than the desire for possession. Therefore he who is contented with contentment shall always be content.'

Another consequence of acceptance is authenticity, to be one's real self. You live fully this moment as it is given anew to you, and fulfill it as best as you can.

The ethical principle of serving the differently abled, therefore, can be summarized as: 'Accompany them on their way (Tao) to their destiny without intruding into their mystery'.

Ethical norms regarding serving the differently abled

1. Since the person suffering from handicaps is a subject with full rights, he or she must be helped to take his or her place in society in all aspects and at all levels, as far as is compatible with his or her capabilities. The recognition of these rights and the duty of human solidarity are commitments and tasks to be carried out. They will create psychological, social, familial, educational and legislative conditions and structures that will favor the proper acceptance and complete development of the disabled individual.

2. The Declaration of the Rights of the Disabled, states, in Section 3, that 'disabled persons have the right to respect for their human dignity. Disabled persons, whatever the origin,

nature and seriousness of their handicaps and disabilities, have the same fundamental rights of their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and as full as possible.'

3. The quality of a society and civilization are measured by the respect shown to the weakest of its members. A perfect technological society which only allowed fully functional members and which neglected, institutionalized or, worse, eliminated those who did not measure up to this standard or who were unable to carry out a useful role, would have to be considered as a society radical, unworthy of man, however economically successful it might be. Such a society would, in fact, be tainted by a sort of discrimination no less worthy of condemnation than racial discrimination; it would be discrimination by the strong and 'healthy' against the weak and the sick. It must be clearly affirmed that a disabled person is one of us, a sharer in the same humanity. But recognizing and promoting that person's dignity and rights, we are recognizing and promoting our own dignity and our own rights.

4. The fundamental approach to the problems connected with the sharing by the differently abled in the life of society can be inspired by the principles of *integration normalization and personalization*.

4.1. *The principle of integration* opposes the tendency to isolate, segregate and neglect the disabled. It goes further than an attitude of mere tolerance. It includes a commitment to make the disabled person a subject in the fullest sense, in accordance with his or her capacities, in the spheres of family life, education, employment, and, more generally, in the social political and religious communities.

4.2. As a natural consequence, there derives from this principle that of *normalization*, which signifies and involves an effort to ensure the complete rehabilitation of the disabled person, using all means and techniques

now available, and, in cases where this proves impossible, the achievement of a living and working environment that resembles the normal one as much as possible.

4.3. Thirdly, the principle of *personalization* emphasizes the fact that in the various forms of treatment, as also in the various educational and social means employed to eliminate handicaps, it is always the dignity, welfare and total development of the handicapped person, in all his or her dimensions, physical, moral and spiritual faculties, that must be primarily considered, protected and promoted. This principle also signifies and involves the elimination of collectivized and anonymous institutions to which the disabled are sometimes relegated.

5. Developments in science and medicine have enabled us today to discover in the fetus, defects which can give rise to future malformations and deficiencies. The impossibility at present of providing a remedy for them by medical means has led some to propose and even to practice the suppression of the fetus. This pseudo humanistic attitude compromises the ethical order of objective values. If this attitude is shown to people of a different category, it would be considered gravely anti-human. The deliberate failure to provide assistance, and instead the attempt to destroy life because it is differently abled, represents a breach not only of medical ethics but also of the fundamental and inalienable right to life. Who among us has the power, at whim, to dispose of human life by claiming that it is not up to our standards? Prevention should be against the illness, not against life. How can any one claim that one wishes to bring comfort to a family by suppressing one of its members because he/she is differently abled?

6. Every attempt, though, must be made to prevent disabilities as far as possible. Present developments in the fields of genetics, fetology, perinatology, biochemistry and

neurology, and other disciplines, give the hope of noticeable progress.

7. The differently abled too suffer from strain and stress that affect their psyche and spirit. They must, therefore, be helped to cope with these challenges. Counselling and spiritual assistance is of paramount importance.

8. When, notwithstanding the responsible and rigorous application of all the techniques and cures possible today, the disability cannot be remedied or reversed, it is necessary to seek and bring about all the remaining possibilities of human growth and of social integration which remain open for the person affected. Apart from the right to appropriate medical treatment, the United Nations' Declaration enumerates other rights which have as their objective the most complete possible integration or reintegration of the person into society. Such rights have very wide repercussions on the whole of the services which exist at present or which must be developed, among which might be mentioned the organization of an adequate educational system, responsible professional training, counselling services and appropriate work.

9. One point seems to merit particular attention. The United Nations' Declaration on the Rights of Disabled Persons affirms: 'Disabled persons have the right to live with their families or with foster parents' (no. 9). It is extremely important that this right be put into effect. It is in the home, surrounded by loved ones, that a handicapped person finds the surroundings which are most natural and conducive to his development. Taking account of this primordial importance of the family for the development of the handicapped person and his integration into society, the family must be made the starting point in planning their programmes and it must be made the principal dynamic force in the process of social care and integration.

10. It is not only the differently abled who would need special assistance in living a meaningful and fuller life. Their close relatives too need support to deal with the situation arising from the membership of the differently abled in their family circle.

11. When particular circumstances and special requirements for the rehabilitation of the disabled person necessitate a temporary stay or even a permanent one away from the family, the homes and institutions which take the family's place should be prepared and should function in a way as near to the 'family model' as is possible and should avoid segregation and anonymity. It must be arranged that, during their stay in these centers, the bonds linking the disabled persons with their families and friends should be cultivated with frequency and spontaneity. Experience has demonstrated-and this is an important point for reflection-that in a favorable and human family setting, full of deep respect and sincere affection, disabled persons can develop in surprising ways their human, moral and spiritual qualities and even, in their turn, bring others peace and joy.

12. The affective life of the disabled will have to receive particular attention. Above all, when their handicap prevents them from contracting marriage, it is important not only that they be adequately protected from promiscuity and exploitation, but that they also be able to find a community full of human warmth in which their need for friendship and love may be respected and satisfied in conformity with their inalienable moral dignity.

13. Children and young people with special needs obviously have the right to instruction. This will be assured to them to the extent possible either through an ordinary school or a specialized school for people with disability. Where home schooling is required, it is hoped that the competent authorities will supply the family with the necessary means. Access to higher learning and opportune post-school assistance can be made possible, and aid should be given for this purpose.

14. A particularly delicate moment in the life of the disabled person is the passage from school to placement in society or professional life. In this phase the person needs particular understanding and encouragement from various sectors of the community.

15. Obviously the differently abled person possesses all the civil and political rights that other citizens have, and it

should, as a general rule, be made possible for him or her to exercise them. However, certain forms of disability—for instance, the numerically important category of those who have intellectual needs—constitute an obstacle to the responsible exercise of these rights. Even in these cases action can be taken not in an arbitrary manner or by applying repressive measures, but on the basis of rigorous and objective, ethical and juridical criteria.

16. On the other hand, the person with disability must be urged not to be content with being only the subject of rights, accustomed to receiving care and solidarity from others, with a merely passive attitude. He is not only a receiver, he must be helped to be a giver to the full extent of his capabilities. An important and decisive moment in his formation will be reached when he becomes aware of his dignity and worth and recognizes that something is expected from him, and that he, too, can and should contribute to the progress and well-being of his family and community.

17. Such persons, their families and relatives are part of the whole human family. However large their number may unfortunately be, they form a minority group within the whole community. This is enough to entail the danger that they may not be given sufficient general interest. Add to that the often spontaneous reaction of a community that rejects and psychologically represses that which does not fit into its habits. People do not want to be faced with forms of existence which visibly reflect the negative aspects of life. This gives rise to the phenomenon of exclusion and discrimination as a kind of mechanism of defense and rejection. Since, however, man and society are truly human when they enter into a conscious and willing process of accepting even weakness, of solidarity and of sharing in others' sufferings, the tendency referred to must be countered by education.

18. Christians have an irreplaceable mission to carry out in this regard. Recalling their responsibility as witnesses to Christ, they must adopt as their own the Saviour's sentiments towards the suffering: 'By this all men will know that you are my disciples, if you have love for one another' (Jn. 13:35).

PERSONS WITH disABILITIES AND HUMAN RIGHTS ISSUES IN REHABILITATION

*R. CUTINHA, S.J.

PART ONE

I. Discovering the Roots

- * The first recorded attempt at rehabilitation of persons with disABILITIES (P-dA) in India was the starting of 'The institution for the Deaf and Mute' in Bombay, in 1884.
- * It was started for the delinquent court-committed deaf children, mainly to obtain the government's co-operation in the implementation of the Children's Act. It was an initiative of the Catholic church.
- * Miss Annie Sharpe, an Anglican missionary, started the first school for the blind in India, at Amritsar, in 1887.
- * Till the close of the 19th. century, without exception, the initiative was by the churches especially the protestant churches.
- * The beginning of this century ushered in government and NGO initiatives. For example, in 1901 The School for the deaf and the blind in Mysore was started by Mr. Srinivasa Rao. In 1909, the government of Punjab, started the Institute for the Blind in Lahore and in 1911, we also have the Calcutta School for the Blind, registered as a society under the Societies Registration Act of 1860, with a board of governors.

* *The President, Divine Light Trust for the Blind, Bangalore.*

- * However, the initiative remained with the churches right up to the middle of this century. Therefore, this period can be rightly considered the 'Christian Era' for the rehabilitation of P-dA.

II. The Christian Era: Bouquets and Brickbats.

- * Education and rehabilitation in those days meant that when a child or person entered the institution, it would be for a long period, if not for the entire life.
- * Given this precept and practice of the period, what could be considered the most positive aspect is that the initiative of the churches tore off the *burka* which shrouded the lives of P-dA and compelled scrutiny of assumptions based on superstition, religion, societal mores and so forth.

(Note: All the countries of the world have passed through 3 phases: Superstition and isolation of P-dA, Institutionalisation, Human Rights and mainstreaming. For example the eugenics theory in USA, with Theologies in support of it found its ultimate expression in the holocaust under Nazis in Germany. Therefore the Indian situation is not an aberration of the Indian people only.)

- * Institutions not only made P-dA 'present' in their respective societies, but also provided the context to confront many of the superstitions and beliefs concerning P-dA.
- * Institutions demonstrated that there were ways and means of making the lives of P-dA more human, and that their existence need not necessarily be *living death*.
- * These institutions provoked other religions to think of their duty towards P-dA and to initiate action for their welfare.

- * However the skills provided in these institutions did not go beyond the 'looms and brooms' variety. Hence when people left these institutions they could not fit into the larger society.
- * Even re-entry into their home milieu was difficult, because institutional care assured basic amenities of life that were far different from the destitute conditions of most P-dA. 'The birds in the golden cage (as a critic of institutions puts it) had failed to master the art of flying in the open.'
- * The institutions were overwhelmingly urban based. This state of affairs has remained endemic. But 80% of P-dA were, and still are, in rural areas.
- * Ecumenism among the churches was anathema in this period. So networking between various Christian institutions was unthinkable.
- * Though the missionaries by and large belonged to the countries of the rulers of India, there was no hard bargaining with the government on behalf of P-dA. In the west the break between the churches and civil authorities was complete. That pattern replicated itself in India also.
- * In brief, The institutions represented a genuine Christian concern and they represent the wisdom of that age. We should consider ourselves fortunate that we can learn so much from the pioneers of the past.
- * But I have one regret: The Christian initiative failed to be the leaven and the salt. Instead, the initiatives petrified into fortresses. May be it was due to 'the minority syndrome' or 'under-siege mentality' which is afflicting the Christian churches in India, even today.

III. 1950s : P-dA comes of age

- * In the 50s P-dA came of age. The credit for this goes primarily to the American Veterans of WW II. America had mobilised the largest voluntary army to stem the onslaught of Nazism and Fascism. There were thousands among these volunteers who survived the war, but were disABLED for life.
- * These volunteers had among them highly trained professionals with successful careers when they joined the army. Now as persons with disABILITIES they were not going to stay idle and nurse their wounds. On the other hand neither the bureaucracy nor the voluntary organisations had the required infrastructure nor the skills to cope with such an unprecedented situation.
- * The veterans took their destiny in their own hands and began calling their shots. They organised themselves, stormed their government, their churches and their communities. They heralded the coming of organisations (not institutions) of P-dA by P-dA. With this they triggered a world' wide movement promoting organisations of P-dA by P-dA. Their battle cry was: NOTHING ABOUT US WITHOUT US.
- * Because of their personal courage, conviction, confidence and commitment they were able to secure their rights through legislation in USA and, thus, promoted similar action in Canada, Europe, Australia and also showed the way to the newly liberated countries like India.
- * The impact of these developments was not lost on the United Nations. And the World Body came out in support of P-dA in a convincing manner. Though the support was belated, nevertheless because of its

worldwide reach, UN instruments have become models for countries like India. Outstanding among UN instruments are:

- 1971 UN Declaration on the Rights of mentally retarded persons.
- 1974 UN Declaration on the Rights of disABLED persons.
- 1982 UN World Programme of Action concerning P-dA.
- 1983-1992 UN decade of P-dA.
- 1993 UN Standard Rules for securing Equal Opportunities, Protection of Rights and Full Participation of P-dA.

- * Thus the initiative of the veterans in USA became the turning-point and that which ushered in the epoch of Human Rights. The focus at present is not on whether there is a need for a separate Human Rights Legislation for P-dA, but on when such a legislation will actually become a reality in countries where it has not yet been enacted.

IV. 1950s and beyond: Achievements of the Government

- * Till the close of 60s India was struggling with the human tragedy that accompanied partition in 1947. Because of this the winds of change did not have much impact on the Veterans in India. And the initiatives of the government were too few, too slow and too late. It is only from the 80s, that government action has gained momentum. Some of the important developments are:

- 1965 : All India Institute of Speech and Hearing at Mysore.

- 1974 : National Institute of Mental Health and Neuro Sciences at Bangalore (NIMHANS).
- 1979 : National Institute of the Visually Handicapped at Dehra Dun.
- 1983 : Ali Yavar Jung National Institute for the Hearing Handicapped at Bombay.
- 1984 : National Institute for the Mentally Handicapped at Secunderabad.
- 1986 : National Education Policy which, for the first time, included children with disABILITIES in a National Document on Education approved by Parliament. Its thrust is to mainstream children with disABILITIES through Integrated Education.
- 1992 : India signs the Proclamation on Full Participation and Equality of P-dA in the Asian and Pacific Region, at Beijing.
In the same year Rehabilitation Council of India Act became law.
- 1993-2002 : Asia – Pacific decade of P-dA.
- 1995 : Bill No: 67 in Parliament introduced on August 26, 1995 Persons with disABILITIES (Equal Opportunities, Protection of Rights and Full Participation) Bill 1995.

* Further there are special employment exchanges, travel concessions, scholarships for education, vocational rehab.centers and reservations from 2-5% for jobs in C and D categories. There are a few universities offering courses in Special Education, Rehabilitation Sciences and in preparing teachers for Special and Integrated Education. Many states have departments of disABLEd welfare.

* The impact of these initiatives can be judged from an observation in the Programme of Action of the

National Educational Policy, 1986. Among the 4.3 million children with disABILITIES in the age group of 4-15 years 'not more than 5% of the Blind and perhaps 0.50% of the Mentally Retarded are estimated to be in special schools... Rural areas where about 80% of the children are located remain practically unserved...'

V. 1950s and beyond: NGO performance

- * This period saw a quantum jump in institutional services provided by NGOs, including church related organisations. It was triggered off by access to funding, especially from expatriate funding organisations. Christoffel Blinden Mission of Germany exclusively dedicated itself to the cause of P-dA, and has probably played the leading role in this development.
- * A definite feature of this period is the initiative of Hindu Mathas to provide institutional services to P-dA, something similar to the church initiatives of earlier periods. Very often these are funded by expatriate funding agencies.
- * After the UN International year of disABLEd persons in 1981 those funding agencies which till then did not cater to the needs of P-dA also began to finance services for them. Therefore, since the mid 80s there seems to be a race to start institutions.
- * Concurrently there has been a growth in the associations for and by P-dA. The more influential among them are:
 - 1992 National Association for the Blind (NAB), Bombay. It is the first of its kind and hence a trend setter.

— 1968 National Association for Equal Opportunities for the Handicapped (NASEOH), Bombay. It is the first trans disABILITIES organisation in India.

— 1978 Karnataka Parents Association for Mentally Retarded Citizens (KPAMRC), Bangalore. It is the first parents association in India.

Besides these, there are Parents Associations for Speech and Hearing Impaired children, Spastic children and others, except for children with visual needs.

- * A very significant development was the establishment of Helen Keller Institute for the Deaf-blind in Bombay in 1977. This was the advent of professional services for persons with multiple disABILITIES in the country. However, the number of such services are few – too few for 2 million persons with multiple disABILITIES in the country (The figure is from the Programme of Action of the National Education Policy 1986).
- * Though these developments in 1950s seem impressive, one should not miss sight of ‘the 5%’ mentioned in the National Education Policy. That is the sum total of NGO and government achievements during the 5 decades of Independence.



PART TWO

I. Human rights and P-dA in India

- * 'With our incredible scientific progress, we have reached a stage where the only threat to human beings left to be met is human beings themselves'. In a zoo in Lusaka, there is cage, the notice on which reads, 'the world's most dangerous animal'. Inside the cage there is no animal but a mirror where you see your self.
- * 'The greatest single idea which humans have given to humanity is that of individual human rights. The concept of human rights has worked its way through the subsoil of human consciousness and has become one of the great driving forces of our time. And the human rights record of States has become the legitimate concern of the international community' (from: a Tribute to UN, by Nani A. Palkhivala).
- * When we enter the realm of disabilities, it will be evident that the concept of human rights (HR) for P-dA has hardly appeared 'in the subsoil of human consciousness' in India. The performance of the Government and NGOs, outlined in the preceding section, should speak for itself.

II. Services for or by P-dA: Analysis with reference to HR

- * Establishing a service for or by P-dA cannot be a testimony to human rights. The motivation may range from 'doing something for the unfortunate' to hoisting the religious flag. It may be purely mercenary in the garb of charity or for securing a platform for promoting one's personal glory. The intentions may be good: to do good, say, to children with disABILITIES who

are neglected in their homes for various reasons. But the means are questionable when we make children dance around someone because of a donation... Such patterns of behaviour condition them to be individuals without self-respect and, hence incapable of defining their own destiny. Institutions should undertake a serious and honest introspection on the methodology of their functioning by answering a single question that is definitive for HR of all: is the human person for the Sabbath or is the Sabbath for the person?

- * A second area to consider is the staff involved in our services to P-dA. We have a galaxy of retired people, pastors and priests, men and women who hardly bothered about P-dA earlier and who present themselves as patron saints of P-dA after retirement. If we are serious about HR of this group of people, then this practice should be questioned. Who is benefiting and at whose expense? Can we really put new wine in old wineskins? Is fiscal control the sole criterion in running services? How different are Government Departments of Disabled Welfare very often run by Bureaucrats, from the revenue department and our institutions managed by retired dignitaries? These and similar questions are applicable to many of the Governing bodies of our institutions as well.

We labour under a fallacy that it is best to keep aloof from politics. Take for example the Persons with disabilities Bill 1995 in Parliament. It is a Bill that is going to define the future of P-dA. Yet how many of the managers of our institutions have taken the effort to study this Bill? How many have participated in workshops on this Bill? How many have lent their voice in sending protest letters, have mobilised signatures in support of well studied and

beneficial amendments to the Bill? Or take the National Education Policy 1986. How many have read and studied this ? Do we have an obligation to apply our minds to such documents?

- * There exists an all pervasive view that anything we offer ought to be good for P-dA and that they should be grateful for it. This is best exemplified in 'looms and brooms' type of vocational training that is endemic. Can we promote equal opportunities for P-dA by condemning them to this type of training? Don't they have HR for training, for an occupation in which she/he can find fulfilment?
- * There is also an urgent need for funding agencies to do a bit of introspection. Who is being funded, the quality of the programmes funded, funding more of the same that has not demonstrated its worth, funding institutions ad infinitum, the lifestyle of funding personnel, their competence and commitment, the corruption involved in sanctioning funding, these and many other related questions are very important. These are directly or indirectly related to HR of P-dA and it is best to quote from the compelling book of Graham Hancock: 'Although funding is a subject of pious literature and is credited with saintly and humanitarian motives, it has condoned the most consistent and grievous abuses of HR that have occurred anywhere in the world since the dark ages (Lords of Poverty).
- * All of us appreciate and applaud the work of Mother Teresa. Her work among 'the scum of the earth' is beyond compare. Her example has challenged people to give their best without counting the cost. Her 'Congregation' worldwide is mute testimony to the

failure of peoples and nations to make HR work. Mother Teresa with her companions provide the matrices of love and care for the rejects of the world.

- * We also know Medha Patkar-the young lady among the tribals along the banks of the Narmada river. She lives with them, organises them, assists them to voice their anguish and in solidarity with tribals and other all over the world, they have transformed the struggle into an HR issue, compelling the World Bank and the Governments in India to have a second look at the Narmada project. This is an example of *empowering* people to be the architects of their lives. Martin Luther King is yet another example who empowered his people to have 'a dream' and to believe 'we shall overcome'.
- * The definite issue in promoting HR of any group of people is the operative word *empowerment*. All our projects and programmes, our staffing patterns, the funding and our varied activities and actions including our motivation should answer one fundamental question: Are we empowering or promoting empowerment of P-dA who come to us? If this question is shirked then we are perpetuating ourselves as 'Lords of Poverty'.

III. The Indian State and HR of P-dA

- * The State has the primary responsibility for promoting HR of its citizens. The Indian State does not have reputation for championing HR. Of late, because of international pressure things are improving. But there is a concealed denial of HR in the functioning of the State. In fact, this denial has become a characteristic of the functioning of the Indian State.

- * Take for example primary health centres. Basic health care, its availability and accessibility, is a right of every citizen. However India is among the 68 Countries that 'have the dubious distinction of not having eliminated polio and thereby denying the World an opportunity to record a major public health success story' (UNICEF-The Progress of Nations 1995).
- * Primary school education is another nightmare. Schools are without proper roofs, floors, without blackboards and seating arrangements, are overcrowded and often in filthy environment, have dysfunctional teachers with pocket calculators struggling to figure out the most economic price for a plum posting, and so forth. Ultimately, it has to be recognised that the meeting of a basic right—the right to education, will withdraw millions of children now condemned to child labour. (UNICEF - Progress of Nations 1995). The performance in the primary school sector is so poor, that India is poised to enter the 21st century with the largest number of illiterates and the largest child labour force in the World.
- * These examples show that India has ignored the basic rights of its citizens with impunity. We do not see any violation of HR by the State in this situation. Instead, we try to be mini Mother Teresas by trying to reach out to some of the victims of the State's neglect and console ourselves that we are doing a great job. We have immunised ourselves from being contaminated by politics.
- * If the basic rights of the majority are ignored, then the basic rights of P-dA do not have any chance. If primary schools system inertia and ineptitude cannot cope with children without disabilities, how can it

serve the needs of Integrated Education of children with disABILITIES? The Government itself admits that 'the coverage under I.Ed is negligible' (National Educational Policy 1986). If unemployment runs into millions, of what use are the special employment exchanges ? Can they create employment opportunities, except for staff manning them ? It boils down to this: HR of citizens and HR of P-dA is indivisible. Whether it is education or health care or employment it can only happen when there is total accessibility for all to education, to health care, to employment and so on.

- * In all HR conscious States, the national support for P-dA is based on legislation, because it compels the State to be accountable. The non-availability of programmes and services becomes justifiable. In India, the support has been without legislation. 2-5% reservations for jobs, for example, look fine on paper. Even today no State in the Country and even the Centre has observed its own order. When Government defaults it is not surprising that non-government establishments also defy the order with impunity. Where does one go to make the Government accountable ? Successive Governments of India have insured themselves from being made accountable in a court of law.
- * The dilatory and evasive tactics of the Government can be gleaned by the persons with disABILITIES (Equal Opportunities, Protection of Rights and Full Participation Bill, 1995.)

— The co-ordinating committee of the Bill consists of 37 members. 34 are bureaucrats and 3 nominated by the Government. Considering the

role they have to play, they are all square pegs in round holes. More important is that none of them are going to take the work seriously, because P-dA have not yet acquired the political clout needed to compel them to work. Parents of P-dA on P-dA themselves do not find a place in these committees. Workers in the field have realised that bureaucracy is the greatest stumbling block. Minister Chidambaram did not say anything new when he said in Delhi recently that 'the bureaucracy is the most oppressive mechanism in the country.' And the fate of the weakest section of our society is handed over to such a mechanism.

- Prevention and early detection of disABILITIES is a separate issue. It is the primary task of health services to prevent disABILITIES. The immunisation programme for example is action for prevention. Take the chapter on Education in the Bill. Totally wishy-washy, showing no recognition of the fact that the Government's performance calls for a radical surgery. For employment and training, what competence does the Social Welfare Department possess? Can it ever match the experience, expertise and the resources of the Ministry of Labour and Training. Similarly all the services mentioned in the Bill can be and should be integrated with the respective National and State Ministries, because these Ministries have the infrastructure needed for the purpose.
- Then comes the bureaucracy of Chief Commissioners and Commissioners while implementing the Bill. Can any single structure take the onus of providing, or ensuring that P-dA are provided services in health, education, training and employment, insurance and so forth ? The

Bill does not allow these functionaries to be made accountable by hauling them to a court, if necessary.

- The Bill does not make mandatory the minimum financing that should go for each service. Consequently, the Government will spare a few more crumbs than it has been till now and much of it will go to the pay and perks of the Commissioners and their staffs. It has been aptly said that the Bill will prove to be a true bonanza for the Babus and the Bureaucrats.
- Tracking of issues relevant to HR of P-dA and Government's action in response, should be great concern to all. In the known history of P-dA, they have faced elimination or marginalisation without respite. The closing decades of this century offered hope through the proclamation of HR of P-dA. In India this hope has been betrayed. P-dA can be said to form the fourth world in this Country and, if one prefers it, the fifth caste, in our caste-conscious Country.



PART THREE

Summarising and problem posing

- * The operative word for promoting HR is 'empowerment'.
- * HR cannot be given. They have to be won. The NGOs should, therefore, prepare P-dA for empowerment through all their programmes and services.
- * This will mean prioritising services and financing those services. It will mean retaining the existing staff and evolving staffing patterns that will promote this concern.
- * An essential part of empowerment is organising P-dA that they may experience the power of their unity.
- * Their organising has to finally become an integral part of the civil rights movement. Without this perspective, the organising of P-dA will be just another way of secluding them from the challenges and opportunities of the mainstream. HR is indivisible.
- * Therefore it becomes necessary to begin to cultivate 'the subsoil of our consciousness' for empowerment.
- * Hence the debate is not *whether* we should do it. That would be a pity and would be unworthy of the goodwill we have. The debate should be *how* best and *how* quickly we can do it.



PERSPECTIVES ON INTEGRATED REHABILITATION WITH SPECIAL FOCUS ON THE LEPROSY-AFFLICTED

DR. G.M. JEYABALAN*

Let me present before you a compilation of random thoughts on leprosy-rehabilitation based on our experiences at St. Luke's Leprosarium at Peikulam in the South of India. It might be better to title this, 'The Peikulam Experiment with the Rehabilitation of the leprosy-afflicted'.

About the St. Luke's Leprosarium:

The St. Luke's Leprosarium at Peikulam belongs to the C.S.I. Tirunelveli Diocese.

A Leprosy Mission-aided Centre, it is basically a referral centre for treatment of leprosy complications not manageable by the GPs, General Hospitals, Government Hospitals, and Government Leprosy Control Units with hospitalization facilities.

The centre has 100 beds, 70 for men and 30 for women, in 3 wards. Free treatment is given to almost 90% of the leprosy patients, without distinction of caste, or creed, thanks to The Leprosy Mission, which meets 33% of the total budget.

The after-care of the Ulcer-Healed

Majority of the patients have loss of sensation which even an MDT cannot restore. The permanent and irreversible anaesthesia of hands and feet continues to hang over their heads like a Democle's sword 'till death parteth them from this world', even after they are declared cured and are removed from the treatment register. They have got to live with this disability—anaesthesia, which predisposes them to recurrent ulceration, particularly plantar ulceration.

**Medical Superintendent, T.D.T.A. St. Luke's Leprosarium, Peikulam, T.N.*

A significant percentage of the patients are of the shepherd community. The only 'trade' known to them is goat farming/sheep farming/cattle farming. Once they are discharged (when ulcer-healed), they go back to tend to their goat and sheep. When the pasture near their home-base is 'consumed', they trek long distances right upto the foot-hills of eastern slopes of the Western Ghats in search of pasture. In the process they ulcerate their feet again. And back they land in the ulcer ward.

To break this vicious cycle, Peikulam Leprosarium is now experimenting with a new project.

The Goat-Gift Scheme

The St. Luke's Leprosarium runs a goat farm. It has a foundation stock of fifty goats.

The vacant land inside the hospital-campus has been planted with protein-rich legumes such as soo-babul and high-yielding fodder grass. The goats are not grazed, but are stall-fed.

During the period of hospitalization potential beneficiaries are identified. After the ulcer is healed, they are 'posted' to the goat-farm for practical training in modern scientific stall-fed goat farming. They learn importance of prophylactic vaccination, periodical deworming and prompt first aid treatment.

After the training, they are sent home with a few goats. The high yielding fodder slips and protein-rich legume seeds raised in the hospital farm are supplied to them. They raise the fodder crop in their own fields.

Most farmers are too poor to have lands of their own. But a good number of them are tenant-cultivators (share-croppers). They are encouraged to raise fodder-crops in a portion of the field in which they normally raise paddy which requires a lot of water. Using a fraction of the water required for paddy, fodder grass and nutritious legumes are raised. They are periodically harvested, cut into small bits,

and then served to the goats. This simple procedure alone saves one third of the fodder cost. It is a big saving considering the fact that fodder cost constitutes 75% of the operational cost of goat-farming. The cut fodder is fed to the goats which are tethered to poles near the fields or impounded in the thatched-sheds. Weaning them off from paddy cultivation and switching to fodder-cultivation met with a lot of resistance initially. Slowly they found feeding goats with fodder crops was one of the most efficient biological machines. It has a high energy-conversion coefficient higher than the profit from paddy. With mutton price spiralling sky-high, marketing goats is no problem.

The goats are dewormed and immunized against all vaccine-preventable diseases.

More importantly, they are insured before being handed over to the patients. The institution takes responsibility for not only insuring the animals but also for claiming the insured amount in the event of death. The patient's responsibility is to report the death promptly and carefully preserving the ear-tag with the insurance proof-mark.

Terms of Repayment

The goats are not outright gifts but are repayable in kind after the gifted goats start kidding. If the goat gives birth to two kids, one is returned to the Leprosarium. They continue to repay at the rate of one kid per kidding until the required number of kids are repaid. The variety given to them is capable of kidding atleast two kids, and sometimes even three.

The Result:

Clinical: Patients who took to stall-fed goat-farming experienced a significant reduction in the ulcer-recurrence rate. Even the few and far between recurrences were simpler and easier for treatment.

Financial: Their income registered an upward trend, while idling thro' hospitalization period was reduced to the minimum.

Social: The ever present ulcer is one of the causes for the stigma attached to leprosy patients. The near-total abolition of recurrent ulcer has made it possible for the patients to be accepted by the family. The patient who was hitherto forced to live in a thatched shed out in the field away from home is now allowed to move back to his home.

Financial cum social impact: It is interesting to note that despite all that is said about the social stigma of leprosy, the leprosy patient who is able to contribute to the family's income is tolerated albeit some grudge. The stall-fed goat farming which has helped generate extra income for the leprosy patient has led him to being accepted by the family.

The healthy members of the family pitch in, harvesting grass and fodder and bringing them to stall-feed the animals.

The family in particular and the community at large are now convinced of the scientific fact that plantar ulcer is not a sign of continued leprosy infection, but an indirect result of painlessness and carelessness. This is indeed health education at its best.

Poultry

Poultry Farming is another 'trade' which does not make excessive demand on feet.

The new breed of poultry called 'Giri Raja' is multipurpose-layer as well as broiler, what more, it is not delicate, but tough. It can be reared in deep litter as well as in the back-yard. The leprosarium receives 3 months' old chicks-all immunized and dewormed through another voluntary agency and supplies them to cured patients. At the end of their poultry farming training, they are given 10+1 or 20+2 birds.

Piggery: A beginning has been made with piggery, making use of the waste from the hospital-kitchen.

Home for Healthy Children

When a husband contracts leprosy, the wife sticks to him thro' thick and thin. The wife seldom deserts a leprosy-afflicted

husband. On the other hand, when a wife is felled by leprosy, the husband very often deserts her, promptly marrying another woman. He forsakes not only the leprosy-afflicted wife, but also his own healthy children born through her. Deformed and disabled by the disease, ostracized by the society, and denied employment, this unfortunate woman often becomes a beggar. Following the mother's foot-steps these children too turn beggars-it is so easy to toe the mother's line. Moving intimately with the undertreated/untreated and often infectious mother, some of them succumb to the infection becoming beggars as well as 'lepers'-a terrible combination indeed.

To prevent this double tragedy, St. Luke's Leprosarium runs a home for such children—Home for Healthy Children. The Home cares for 60 children (32 boys and 28 girls). All of them receive total care—food, shelter, clothes, medical treatment and schooling—all free of cost. They attend a 'normal' school in the neighbouring village. After their schooling, they are given job-oriented technical education.

Thanks to the World Missionary Evangelism, Dallas, Texas, USA. This Home provides assistance to the really destitute who are on the verge of poverty and beggary.

Other healthy children of leprosy patients are not dislocated from their natural milieu but are encouraged to attend school in their home-towns. The Leprosarium extends all possible assistance through gifts of books, school uniform and clothes.

Comprehensive Health Care

When a patient reports for treatment, as a routine the entire family is checked up thoroughly. The procedure does not end with examination for early evidence of leprosy. The children are given all vaccines besides Vit-A.

The healthy members of the patient's family are offered general medical treatment at a subsidized rate—often just the cost of drugs.

The Results: The General medical treatment and comprehensive health care extended to the family raises the 'stock' of the leprosy patient in the eye of his family and community, contributing to his being accepted.

It is not a rare sight to see a general patient in need of general medical treatment, roping in a leprosy patient of their community to 'recommend' their case to the doctor.

Needless to say, the patients' attendance rate is high.

Some of the 'extra-miles' run by the institution:

1. St. Luke's Leprosarium assists the leprosy patients and their families in obtaining Old Age pension and Handicapped pension.

2. Free Eye Camps are conducted every 3 months at the Leprosarium premises which is open not only to leprosy patients but also to the general public.

A lot of these efforts are due to the support of our parent-organization, the St. Luke's Hospital, Nazareth and their financial supporter, the Christoffel Blinden Mission, Germany. Thanks are also due to the Central and State Governments, who conduct free Eye Camps, in St. Luke's Leprosarium under the National Blindness Control Programme.

Though pride of place is accorded to leprosy patients and their families, the non-leprosy public participate in large numbers.

Conclusion: Most of these observations may be too simplistic, many may be stating the obvious, and some may be repeating the already well-known. None of it is novel or revolutionary. But one thing is guaranteed. All of this is born of down-to-earth practical experience.

Rehabilitation of the leprosy afflicted is difficult. But unless rehabilitation and treatment march hand in hand, the claims of the curability of leprosy will be questioned. Rehabilitation efforts after MDT and RFT (Removed from treatment register) is a must for achieving the goal of leprosy eradication.



THE WAY WE VIEW THOSE WHO ARE DIFFERENT FROM US

*DR. M.C. MATHEW

This is a response to the ongoing discussion on the issue of terminology that is used to refer to those with 'disability'. This needs our attention. Is there a christian view point on this?

Let me approach this issue from three different angles:
(1) Historical (2) Biblical (3) The person with special needs.

Historical

In the history of medical development, the science of rehabilitation is a fairly new speciality, going back to perhaps 60 or 70 years. Before this, for over 300 years or so, people who were different from the normal were described by different terms. If a person was extremely poor in his abilities, he was considered an 'imbecile'; if a person was physically needy, then he was considered 'invalid'; if a person was not able to cope with a normal lifestyle, he was an 'idiot'; if a person was not so successful in his career, he was a 'fool'. Even today in the field of Psychology, we try to classify people on the basis of their Intelligence Quotient. Psychologists describe people with an IQ score in the range of 90-110 as normally intelligent; those with 70-90 as below average; those with 50-70 score as educable and those below 50 as trainable. Even though this is a scientific method, this is also another way of classifying people on the basis of their performance level. We are moving away from this concept. The professionals are beginning to describe people by referring to their functions. So we have been using terms like blind, deaf, orthopedically handicapped, intellectually impaired. Once again this terminology highlights the need or the lack in a person, thereby projecting his negative attribute. This is largely the creation

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of professionals in order to specify the disability of the person. Several disciplines of science of rehabilitation, like Psychology, Special Education, Occupational Therapy, Physiotherapy, Orthotics, Prosthetics, Developmental Paediatrics, Child Psychiatry etc, have developed in the last 50 years or so. Professionals describe people, based on their functional disability inspite of a good deal of opposition from people with special needs.

The recent concept (particularly in the last 10 years) has been to evolve a more positive and holistic approach toward people with special needs. So the terminology is shifting to describe them in the light of their needs or abilities. The advocates of this approach are mainly people who have special needs themselves or their family members. Many professionals having seen the wisdom of this approach have taken note of the psycho-emotional dimension of one's personality when he or she has special needs. So it is common now for us to hear people with special needs being referred to as those with hearing needs or visual needs or language and communication needs, mobility needs etc. This essentially creates an atmosphere of commonality with others. Anyone of us can have a visual need requiring spectacles or a mobility need requiring a walking stick. The needs may vary in intensity and pattern from person to person. The needs cannot be the reason for classifying or segregating people. What is common between those with special needs and the rest of us, is that all of us have needs and what separates the two groups is only the difference in the intensity of the needs. It is the uniqueness of a person and his or her worth that needs affirmation and expression, rather than his or her special needs. Some slogans like 'Look at me and not at my wheel chair' or 'Some say I am handicapped, you say I am a Downs, but I am Jyothi' communicate the hidden grief that people with special needs carry in their hearts.

In a recent conference at New Delhi this came up again and majority of professionals consented to welcome this new approach.

Biblical

The biblical overview of life is that life is a gift from God. (Psalm 139 vs. 14-16). In the Genesis account of creation, in the first two chapters, we see a further expression of a creative act of God. So God is at work in giving form and shape for each person. The reproductive process is a physiological function taking place under the oversight and control of the Master who causes all things to be formed according to His goodwill. It is His Sovereign will which is at work because of which people are born differently. (Exod. 4:11).

Jesus befriended people with special needs such as those who had hearing needs, visual needs, epilepsy, leprosy etc. What is clearly seen in these healing stories is the compassion of Jesus. The compassionate response is a consequence to being touched by the pain and suffering of those with special needs. So, Jesus looked at people with interest; He touched some of them; He pronounced forgiveness of sins for others; He offered physical restoration. All these indicate how Jesus was involved in restoring the full potential of each person.

In the story of healing the blind man, when His disciples asked whose mistake was it that he was born blind (John (9:3), Jesus responded by saying that, 'This happened so that the work of God might be displayed in his life'. In some situations (Luke 5:20), He offered forgiveness of sins, before He provided physical restoration. In one situation, He asked those with leprosy to go back to the High Priest during which journey they were healed. (Luke 17:14). In this case, physical restoration was made possible through renewing relationships. What strikes me in the healing miracles is how Jesus restores what was being lost, rather than labelling the disability or discussing the cause of the disability at great length or highlighting the disability itself. We are reminded to regard human life, in terms of its potential and hidden resourcefulness.

In the story of Moses, Moses confesses his inability to respond to God's call. However God affirms Moses through

His special intervention of performing two significant miracles. (Exod. 4:2-7). God was giving Moses a lesson in his worth and value when God is beside him. There was no exposition of his criminal and ugly past at that moment. The past remained covered once and for all. In the life of a person having a disability, what is needed is to cover that which has caused him hurt, pain, suffering and agony by an affirming statement of acceptance, welcome and self-worth.

In the case of Peter, we did not see Jesus referring to Peter's denial of Jesus or deserting Jesus in the garden of Gethsamane or at Golgotha. Instead Jesus goes after Peter to find him fishing (John 21:1-17) and finally seeking Peter to respond to Jesus's invitation—'Do you love me ?' I find this approach very moving. Jesus was able to look at them through the optic of consideration, compassion, understanding and affirmation. There is a deliberate effort needed to dissociate the background from the present. The present is different from the past. When we view people with special needs, we as Christians are invited to bring into the present, a ray of hope, a message of affirmation and an invitation to look beyond their immediate needs to appreciate the goodness that accompanies their lives.

We are all members of the body of Christ, each contributing to the other in upbuilding the Church. Just as there are different parts in the body—some small and some—big—all of them jointly working together, we need to bring into our daily living context, this attitude of being related to each other on the basis of Christ being the head of the body. This overview should enable us to work together for strengthening this unity rather than creating differences within the 'body' by referring to them with regard to their economic status, nationality, physical abilities, profession etc.

Those with special needs are at the heart of a Gospel. In the Nazareth manifesto, we find the centering of the ministry of Jesus around those with special needs (Luke 4:18-19). The ministry of Jesus was to liberate them from their position and suffering and to give them a hope and a future. It is this

ministry that we are called to continue. We are therefore committed to bring the ministry of hope through the way we describe people having special needs and associate ourselves with them. Our terminology ought to convey this message of hope and loving invitation for partnership with them to find meaning and purpose beyond suffering.

The least members in the body of Christ are more honourable than the others (I Cor. 12:24). St. Paul talks about God choosing the foolish things of this world to confound the wise and the weak things of the world to shame the strong (I Cor. 1:27). Jesus honoured little children who according to the disciples did not deserve much attention (Luke 18:16). These instances suggest the special value and honour that God may attribute to those who are different from us because of their special needs. There is something in them which is missing in the lives of the rest of us. We are made more complete by being able to receive what they have to offer us. Jean Warnier, founder of L'arch refers to people with special needs as 'wounded healers' through whose ministry we are enabled to discover a new measure of wholeness in our lives. We ought to therefore honour such people whom God honours with honourable words.

The Bible has a tradition of giving new names to people. Abraham and Sarah received new names. Jacob received a new name. Peter received a new name. This tradition of giving new names is a tradition which God established to indicate that God makes something beautiful out of weak, vulnerable or fragile people. God introduces us to this tradition of looking at the future. So when Abram became Abraham, God saw him as the Father of the nations; when Jacob became Israel, God saw him as an overcomer; when Simon became Peter, Jesus saw him as a rock. These new perspectives affirm God's purpose for individuals. I believe that it is important for us to reflect God's perspective when we use terminology to describe people with special needs. God uses even the least among us to fulfil a purpose which is significant in the family of God. We ought to look at this Biblical tradition of giving

names to people as an authentic expression of God's affirming purpose.

Our Christian heritage invites us to create a counter culture in the professional realm of rehabilitation. The rehabilitation science looks at the existential reality and offers to alleviate the sufferings of people. This is the only perspective that scientific medicine can bring in, because it is constantly engaged in finding avenues for physical restoration. When restoration is not possible, the scientific profile fails. The science of rehabilitation therefore is a special situation where the limitation of medicine and the struggle for rehabilitation become apparent. It is a discouraging and depressing situation leading to dismay and anxiety. As Christians, we are faced with this reality of having been called to transform this depressing environment to a hopeful environment.

We are asked to bring meaning and purpose in the midst of pain and struggle. We can do this only by viewing people, their needs and limitations from a different angle than what the medical science is used to. We need to be open to what God can do and trust in the ministry of healing beyond the realm of medicine. We need to look at the scenario through the optic of possibilities. It is this optic of possibilities that we ought to articulate through the terminology that we use while referring to people having special needs.

The Person with Special Needs

Having spent most of my time with children and parents with special needs in the last eleven years, I am surprised by the discoveries that I have been able to make. To be involved with about 3000 children, is demanding, stressful and sometimes difficult to cope with. But that is not what is uppermost in my mind. What I am surprised to find is the tremendous resilience, courage, confidence and capacity with which the children and their families adjust to their special needs. Excepting in the initial phase of the grief cycle, I have found that most parents have been able to welcome their children having special needs with a new measure of appreciation. So

much so, some parents have even talked about the privilege, that has been theirs, to care for their children. Many parents have warmly, although tearfully, talked about the new insights and rich experiences which they have received through the presence of the child having special needs in their home. I have seen scores of mothers taking up professional training to help children with special needs, following their experience at home. I have seen siblings of children having special needs go into training to equip themselves in the field of rehabilitation. I have seen Church groups rallying around the families to support them because of which there was revival in some congregations. There are instances, that I can recollect, of people and small groups receiving a vocation through the encounter that they had with people having special needs. Although this is not an exhaustive reference to the tremendous impact that people with special needs have on us, I am tempted to think that what they contribute to the well-being of all of us is sometimes lot more than what we have been able to share with them, to make their living better.

Our present terminology denies an overt expression of this powerful aspect of their transforming presence in our midst. Infact, our repeated references to them by highlighting their difficulties may add insult to their already hurt feelings. Many of them struggle daily to recover from the hurt and to experience healing. Our present terminology is a further reminder of this hurt and repeats the cycle of grief within them. The way we describe them can either take them back to their grief cycle or liberate them into a growing phase.

If there is so much of worth and resource in them because of which they overcome their struggles to be catalysts in society, why do we stick negative labels on them? A person with visual needs is a scholarly professor in the University; a person with a hearing need is a scientist of reputation; a person with physical needs of mobility is a leader in the field of computer science; a person with communication needs is a reputed artist and creative therapist—the list is long. Those of us who have fully developed faculties may not be able to

match their special skills and abilities sometimes. Their exceptional achievements speak of their ability and confidence to overcome struggles of daily living. They have faced the challenge and conquered their trials in a spirit of adventure and perseverance. Most people with special needs carry such a measure of resourcefulness that we ought to bring that into focus while we refer to them through our terminology.

Many parents have tearfully shared with me how they feel miserable when their children are referred to as 'mentally retarded'; 'mentally handicapped'; 'disabled' etc. They look at the society around them as hostile and insensitive. Some of them would even argue that we have made them 'disabled'. Some families have shared with me instances of their children not being able to go to school because they cannot climb the flight of stairs with a pair of crutches. Those children with abilities to study have been denied the opportunity because we have underrated their abilities or overlooked their special needs. This reflects the unpleasant effect of projecting the limitations or disabilities with which they suffer. If only we can highlight in discussions and terminologies, something of their infinite resourcefulness and possibilities, then we are able to redeem them from their struggling profile. How wonderful it would be, if, as Christians, we can create an environment in which people having special needs grow, prosper and blossom. We need to begin to affirm that possibility by using an appropriate terminology which is uplifting and affirming.

Some practical suggestions

Let us refer to people having special needs in creative ways. Some of those creative ways may be:

- (1) People with different abilities.
- (2) People with special needs.
- (3) A child with learning needs-ex. Varun having learning needs in the area of memory.
- (4) People facing challenges (Annie facing the challenge of walking and communication).

(5) People with adjustments to make (Kenny having to adjust to his hearing need).

Some of these suggestions are reflections of some people who are in direct proximity to people having special needs. These terminologies may appear long or perhaps clumsy. It is important for us to recognise that new terminologies are in the process of evolution.

What is needed therefore is to consciously abandon terminologies such as 'retarded', 'handicapped', 'disabled' etc. We have a responsibility to create a new awareness of the philosophy behind this approach which is historical, biblical and based on the needs of a person having special needs.



BIBLE STUDY

*REV. J.D. SOLOMON

Gospel Reading: II Samuel 9

‘Open thou my lips, O Lord, and my mouth shall show forth thy praise. In the name of the Father, the Son and the Holy Spirit. Amen.’

There were references during the course of this consultation to the word ‘compassion’ and to phrases like ‘human rights’ and ‘justice issues’. There was a specific reference to ‘the differently abled being ‘the architects of their own destiny’. How far are these really possible? There does exist a certain amount of confusion among those who work in the field of the differently abled—they ask themselves, are we working for them? Do they need to work solely on their own or does our work have to be more participatory ?

One particular area where I, along with Dr. George Joseph have been engaged in, for sometime, is the involvement of people as congregations in caring, rehabilitative programmes. My assumption is that the Bible Studies are one of the most helpful foundations in equipping a congregation or any denomination in such an endeavour. I was encouraged by the references yesterday that the whole context of our deliberations is in the area of the Church’s missional engagement, which is part of our missionary exercise seeking the role of the Church as a missionary body in a particular area.

In Matthew and Luke, we read about John the Baptist who first introduced Jesus of Nazareth to the public of that time. He said: Look, here is the lamb of God, who takes away the sin of the world. Later we read that John got offended even to the point of being skeptical of this very same Jesus whom he pointed out as being the Messiah. John,

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I would say, is fortunately in prison at that time. Otherwise, there could have been an open encounter on the streets of Jordan. Helplessly, John sends some of his disciples to Jesus to tell him: Look, I am totally confused. Are you really the Messiah I was hinting at or am I mistaken? Jesus's answer is very straight and simple: 'My friend, the very same actions of mine which offended you, are the very proof that I am exactly what you witnessed, a few weeks ago' (Luke 7:18-23). In verse 22, we read that Jesus had just then cured many people of diseases, plagues and evil spirits and had given sight to many who were blind.

The same chapter reveals two incidents of Healing. One is the healing of a centurion's servant. A very typical example of Jesus's Healing Ministry. A centurion is a Roman officer, a gentile, an outright condemned man. That is qualification number one. Qualification number 2 is that the person cured is the centurion's servant boy. It means 'a slave'.

The second incident is that of Jesus giving life to a widow's son. No recommendations here, just straight interference. Yet more important is that the boy was a widow's son. But how did Jesus respond. 'My daughter My daughter, your son is living.....' No wonder John is offended.

Luke's model of Jesus has many a time been dramatic. When Luke introduces him in Chapter 4, Jesus is on his way back from the wilderness—where he was tempted—full of power, to start his ministry. Probably on that Sabbath he was in the synagogue in Nazareth. It is a very dramatic performance that Jesus gives in the synagogue. The scroll of Isaiah was given to him. All eyes were on this young man, the new teacher who has come on the scene. Then, from one end, he rolls and unrolls the scroll till he comes to Chapter 61. He reads the passages, goes over and sits down. I don't know why he does that when he knows that everybody is looking at him expectantly. Then Jesus gets up and says, 'In my reading of this scripture, this is being fulfilled'. This was the opening sermon of Jesus, and was a very controversial and outrageous one. He just narrowly escaped the scene.

Similarly in the famous (or infamous) Nazareth manifesto. If the Nazareth manifesto is Lukean manifesto, Matthew and Mark also have similar passages giving opening words of a new Rabbi (Matthew 4:17, Mark 1:14,15). If we put all the three together we will get a near total picture. The only difference is that in Luke there is no reference to the phrase 'Kingdom of God', unlike in Matthew and Mark. But is certain that Matthew, Mark and Luke are all speaking about the 'Kingdom of God'.

Luke has a particular style, with a particular emphasis on introducing Jesus. Introductory statements about Jesus in all the four gospels are developed upto the final statement of Jesus, called the 'commission'. Luke's particular way of expressing Jesus' commission is seen in the phrase 'forgiveness'. What is forgiveness? What does it imply? Reconciliation, acceptance and repentance. These are the commissions Jesus gives through the words of Luke.

In Isaiah 61, it is said 'for the poor, the deaf, the blind, the lame, the imprisoned....' Let me remind you that Isaiah 61 is a single statement. In the very same book of Isaiah we would have to look into several situations to understand this statement of Jesus. As he was unrolling the scroll in the synagogue, he kept in mind the references in the previous chapter and finally when he quotes from the last chapter, he does so with the support of the previous chapters in mind. For eg. he remembers Is. 29:18; 42:3-5. The passages refer to the positive outlook, the hope and the brightness coming to the people of Israel and through them to the whole world. So also, Is. 35:5,6 which speaks about the transformation that it going to take place among man, humanity, nature and animals. Is. 29:18 says 'on that day the deaf shall hear the words of a scroll'. It could very well mean that those who have not till now touched a word of God would now read the scroll of Isaiah. 'The blind will see, the deaf will hear, the lame will leap and dance, the burning sand will become a lake.....' 'The wilderness and desert will blossom and rejoice, break forth of mountains, into singing and dancing...'

Omnipotent God reigneth. LET THY KINGDOM COME.

In the messianic time which is fulfilled and inaugurated in Jesus Christ, the truth is that such unbelievable and impossible will become a day-to-day event. The kind of action that Jesus started will continue and spread throughout the whole world, in bigger dimensions. Jesus's people will execute, like their Lord and Master, such actions according to the mind, heart, will and wish of the Heavenly Father. That is what makes it holy and that is the privilege God gives to his people.



REFLECTIONS ON THE THIRD DAY'S PROCEEDINGS

*DR. M.C. MATHEW

During this time of reflection in the last two days, I tried to present an overview of the various deliberations. On the first day I referred to the history of our approach to rehabilitation, the story of models and the frame of reference, the congregation. Yesterday I referred to a journey that we are in, journey into ourselves, journey into the world of realities, and journey into the future.

One of the most outstanding insights that we received yesterday during our deliberations was the experience of one particular hospital in South India wherein the hospital receives a very lively and active participation from the congregation. Not only is it financially supporting the ministry of the hospital actively, but the members of the congregation are also at the very centre of the activities and programmes of that hospital. All the three days we heard from various speakers about the primacy of the congregation in upholding the ministry of rehabilitation. Because it is at the heart of the congregation there is this vibrancy which is required to reach out and embrace people who are different from us. In the light of that moving story that we heard, as well as other instances, I want to summarise these reflections on the past two days, especially yesterday, by referring to three dimensions-first, the mystery of life, second the sanctity of life, and third the call of life.

We heard yesterday *'let us accompany people in their journey without intruding into the mystery of their life. This was described to us as 'active non interference'.* What is this *mystery of life?* Mystery speaks of hiddenness. Life has two dimensions-the visible dimension and the hidden dimension. The visible dimension of our lives is our body, which has

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the usual physiological functions of seeing, hearing, feeling, talking, behaving or walking. In the last four days we have been told of the variation that can happen in the life of a person who is otherwise able wherein the faculties of seeing, hearing, feeling, communicating, walking, etc, are in some way or the other affected. They are affected because their physiological processes have in some way been touched by an 'insult', leading to changes in their body. It is their body which bears the marks and scars of that insult which they have suffered. And yet however disfigured or different that body may be, if I were to quote St. Paul from II Corinthians 6, 'this is the temple of the living God'. It is this Christian understanding that helps us to understand the other dimension of our lives-our hiddenness. If the body is the temple of the living God, then this very life is honourable to God and ought to be honourable to each other. What makes this body, inspite of all its limitations and disability honourable before God is, again quoting from St.Paul Colossians 3:3 'our life is hidden in Christ'. This hiddenness is in contrast to what is revealed. What is revealed is visual impairment, hearing impairment, quadriplegia, paraplegia, leprosy and what not. But what is hidden is the earthen vessel in which the treasure abides. This very body is subject to mortality, morbidity or disability and therefore decay. But the treasure that is hidden within is imperishable and beyond the touch of any disability. It is eternal.

This gives us a new optic to look at people who are different from us. If you look at them through the scientific eye of their disability then we describe them as disabled. But if we can train and tune our eyes to see them through the optic of God who sees them 'as the temple of the living God' then we move towards beholding them as those whom God has allowed to be present among us.

We were told yesterday that the saints sometimes appear to be very insane. But their spirituality was accompanied by commitment to Jesus Christ, sometimes even disproportionate to what was normally possible for them. This is the mystery of life that those who are different from us have this immense

capability to behold the goodness of God which you and I sometimes cannot. Therefore, our involvement with those who are different from us is not to provide services for them but to seek to know them as they are known before God. This is the mystery of life that they in their body, bear the treasure of life.

This leads me to the second dimension, the *sanctity of life*. Sanctity refers to sacredness. In Ps. 129:13 we are told, 'thou didst form my inward parts, thou didst weave me in my mother's womb, I am fearfully and wonderfully made'. Every person is fearfully and wonderfully made. No disability is accidental in the sight of God if we believe that God has paid special attention to the very formation of every person. Alan Jones in his book 'Journey into Christ' talks of a dazzling darkness when he refers to God. God's radiance is so brilliant that it causes darkness to the beholder's eye. St. Paul was blind for 3 days following his brilliant encounter with God on the way to Damascus. Although Moses saw only the rear of God it caused a permanent radiance on his face which others could behold. The disciples could only have a veiled vision of God on the Mount of Transfiguration. God is a dazzling darkness that we can see, only if he is covered with a veil, lest his dazzling darkness consumes us.

Disability is that darkness that God uses in the lives of some, for us to have a distant view of God. The image of God is made manifest in the lives of some through the disability that they bear in their body. They are made to carry it in their body so that we get a glimpse of God. Infact those with disability suffer in their body in order that through their suffering they bring a saving experience to our souls. That is why their life is sacred. That is why we need to regard the sanctity of life as the foundation for our approach to those who are different from us. Those who are different from us, therefore bear the mark of sanctity and not the scars of disability. So let us not just talk of their rights and equal opportunities alone, but let us begin to honour them with our

special attention because they are the messengers of God in our midst. They announce to us the Kingdom of God. 'Blessed are the poor in spirit, for theirs is the Kingdom of God'. Those who are differently abled are battered by the tensions and stresses of life, their spirit is impoverished and yet theirs is the Kingdom of God. Because through their disability they hide the dazzling brilliance of God so that we get a glimpse of God.

I referred to the mystery of God—the mystery of life and the sanctity of life. Let me now refer to the *call of life*.

When we are in the company of those who are different from us, we can be touched by the mystery and sanctity of life. We encounter the hidden God and also the dazzling darkness of God in them. So our call in life is to accompany them—accompanying being a means of keeping pace with them, not going ahead or lagging behind. So the call is not to make them 'normal' or to make them confine to our patterns and designs of life, but to be surprised by the mystery which they are before us, and before God. We also should not and need not leave them behind, because then they suffer alienation.

Then, the call of life is to accompany them and build our lives around them, because they hide the treasure of God in their lives and their disabilities are ways in which we can behold God. They are the wounded healers in our midst. It is being in their company that we experience healing for ourselves. Healing is restoration. Accompanying those who are different from us therefore becomes the source of our own inward healing.

Little outside Zurich in Switzerland, there is a natural spring which brings forth warm water. This natural spring has a healing property to those with back'aches, arthritis, spondilitis and various forms of neuro-muscular disfunctions. Many people from far and near come to have a water bath in the spring. And they find relief to their symptoms and return rejoicing. Those who are differently abled are the natural spring to whom we may come to find healing for ourselves.

The funding agencies may have their own agenda as they get involved with people who have different abilities. The institutions and organisations also have special agenda as they befriend people with special needs. The professionals have their own agenda as they associate themselves with the care of those who are differently abled. The national and international governments may have their own agenda as they get involved with people who are differently abled. So there comes this question to us, what is *our agenda* when we decide to accompany them in the journey of life. Can it be that our agenda is that of knowing them whom God has sent into our midst. In knowing those who are differently abled we are drawn towards God to appreciate the mystery of life, the sanctity of life and the call of life.

The last three days that I have been here, I happened to watch that water spills from the overhead tank here every morning. One may look at that and say, 'what a waste of water'. But as I kept watching, I realised how birds from the air come to the overflowing water to drink from it. For us, that overflowing water is a waste, but it is a gain for the birds of the earth.

Disability is never a waste. How much ever we are told by the materialistic world about the enormous resources needed to take care of them. Their disabilities are gains, because they show us the way to God.

I want to conclude by saying how I myself was greatly touched and inspired by a moving example in the life of a congregation in this city of Madras. This happened about 6 years back. This congregation had around 15 children who were differently abled. The Pastor and his colleagues wondered how they could bring them into the full fellowship of the church through confirmation. Being differently abled, they could not go through the normal preparation for confirmation. The Pastor and his colleagues decided to conduct confirmation classes for them through symbols, drama, music and various forms of therapy so that they could be built into the knowledge of God and have a personal faith in Christ. 15 of them had

their confirmation service after about 6 months of preparation. Eyes were wet as the congregation witnessed how these very children whom they had kept outside, when brought into the full fellowship of the congregation, were given the grace to have a new glimpse of God.

It is in this journey that we are engaged in as we accompany those with special needs in the journey of their lives.



COMMUNITY BASED REHABILITATION (CBR) IN INDIA

Issues and Future Concerns— an overview

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Written history shows that care of persons with disabilities started somewhere in the 18th century. Most of the care was carried out through homes for the poor, asylums, institutions, hospitals and schools, majority of which were managed by religious missionaries. This continued throughout the 19th century mainly because of an attitude of charity and welfare.

The Constitution drawn up for independent India in 1950 reflected this attitude. It contains a sentence referring to 'relief of the disabled and the unemployed'. The Government of India initiated many schemes and programmes for the benefit of persons with disabilities, like pensions, grants for schools for differently abled children, subsidies, reservation of jobs, etc. At the same time planners were also looking for liberalisation of services in the health and education sector. In 1969 the World Health Organisation in its technical report suggested that rehabilitation should be a natural and essential component of health care. The Alma-Ata declaration of 1978 also reinforced this and stated that the principles of health-for-all-by-2000 AD should be made applicable to persons with disabilities as well.

Systems for rehabilitation that existed during those times were not conducive to universal coverage. The institutions set up provided very little coverage and was centered in urban areas. And thus started the search for more cost-effective, community or home-based approaches for rehabilitation. Simultaneously the WHO started promoting the CBR approach which was further supported by world bodies like ILO and UNICEF. The CBR approach was suggested as an alternative

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for developing countries, where majority of the people lived in rural areas. The principles of CBR, were (a) coverage (b) cost effectiveness (c) community participation and (d) integration. Though the principles of CBR are universal, the implementation of CBR differs from country to country and from place to place, depending upon socio-economic, cultural and political factors. Hence it is essential that each CBR programme understands and defines for itself what CBR means.

What is CBR?

To majority of the CBR programmes in the country, a 'Community' is a geographical area and includes all members of that area irrespective of caste, religion, colour and creed. 'Based' indicates that activities are carried out at the community/family level with participation and contribution from the families and the community members. 'Rehabilitation' is comprehensive (medical, educational, vocational and social) and involves all age groups and all categories of disabled people in a given community.

CBR is in its evolving stage in India. The effective development of CBR in India depends on certain factors, some of which are detailed below.

Training of manpower for projects at the community and family levels is a must for effective CBR programmes. This training must be regular, ongoing and towards helping people with disabilities to meet their day-to-day needs. The specialised skills required in rehabilitation should be transferred to lay people in the community, as much as possible. CBR Projects should ensure that persons with disabilities get appropriate and affordable technical aids. Regular and continuous follow-up should ensure that technical aids are used appropriately and effectively. Information on the latest developments in the field of rehabilitation should be available at all levels—from the grass-root to the policy-making level. In the absence of information, there is a possibility of reinventing the wheel, committing the same mistakes or duplicating research. CBR programmes should ensure community participation through formation of formal and informal groups. Efforts should be

made to include persons with disabilities and other prominent people in the community on Boards and Advisory Panels of projects. This will help in increased acceptance of programmes in the community. All CBR programmes require a network of referral and support systems for effective functioning. Projects should ensure quality of services, right attitude of staff and that policies and programmes at the referral centres are conducive to a CBR approach. In today's scenario, very few communities are socially and economically capable to initiate rehabilitation programmes on their own. Hence most of the CBR projects work as catalysts in communities, making communities capable of managing their own people with disabilities. If CBR programmes do not work as catalysts or facilitators they will continue to be only service providers. The project management of any organisation which plans to take up a CBR programme should have a decentralised approach, in terms of administration and service. The emphasis of CBR should not only be on the number of people who are covered in a programme but also on the quality of the services provided and the impact the services have on persons with disabilities. Appropriate monitoring and documentation of projects is imperative to measure their impact.

CBR raises many questions. Is it the right and best approach? Does not quality suffer in CBR? Would communities really participate? Only research in the particular community can answer many of these questions. The only way to ensure that CBR works, that it benefits people with disabilities and their families in a sustainable and cost effective way, is to continuously study the process of CBR in all its aspects. CBR projects should look into what the future role of persons with disabilities will be. Are they going to be mere beneficiaries? To what extent are they going to have control over their own lives? Rehabilitation programmes today are not part of development. Can rehabilitation programmes continue to be isolated from development? Should CBR projects take up developmental work, and vice versa. An integrated disability development approach is seen by many these days, as a viable alternative.

If the field of rehabilitation is to grow and develop in a directed fashion, it is imperative that the country develops a National Policy on Disability and Rehabilitation and ensure that it is translated into action.

CBR has now grown from embracing a service-delivery approach to being a comprehensive philosophy of empowerment of people with disabilities.



ISSUES IN HEALTH AND REHABILITATION OF PERSONS WITH DISABILITIES

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Persons with disabilities are multiple disadvantaged. Disabilities are much more common among the socially and economically disadvantaged. The World Health Report, 1995, 'Bridging the Gaps' opens with this statement:

'The world's most ruthless killer and the greatest cause of suffering on earth is extreme poverty—Poverty is the main cause of reduced life expectancy, of handicap and disability and of starvation'.

Poverty in India over the years, has become more acute. A recent poll conducted by INDIA TODAY-MARG (India Today, April 15, 1995) has reclassified three hundred and fifty millions of India's population, as poor. Of them, two hundred millions are *destitute*.

The economic liberalisation and *privatization with commercialisation* have made more people poor and the poor poorer. The International Monetary Fund and World Bank have pressurised the Government to change the direction of economy. The Structural Adjustment Programme is a condition for giving loans. But it leads to reduced allocation for social services, including health, and it imposed hard burdens on those who were already suffering.

The Emerging Scenario

The Policy Delphi Study carried out in 1990 showed the likely future trends during the next fifteen years, in various spheres. These will have important effects on health and rehabilitation of persons with disabilities.

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Economic

- * More and more devaluation (Rupee sliding down against foreign currencies), commercialisation and privatisation; increase in the gap between import and export and increased need for repayment of loans.
- * There will be decreased government spending. This will be primarily in the social services and development sector. Subsidies to health, education and housing will be decreased. The health status of the poor will deteriorate, they will be unable to avail of the privatised health services. Cost of diagnostic and curative medical services will rise at a galloping pace.
- * The economic process will benefit the business and industrial groups. The majority, comprising marginal farmers, unorganised workers, landless labourers and daily wage earners, will not benefit. Children, women and the illiterate will suffer the most.

Positive factor: More people may be brought above the poverty line.

Social

- * Increased breakdown of families; inadequate care of the aged population.
- * Increasing urbanisation, with inadequate basic facilities for the poor.
- * Progressive erosion of values. Prevalence of a narrow sense of individualisation.
- * Increase in regional, linguistic, communal and caste conflicts.
- * Increased consumerism.

Positive factors:

Improvement of education, especially of women. Science and technology improving the life of the average person.

Increased focus on ecological and gender issues.

Political

- * Political instability. Corrupt and self-seeking politicians dominating the political scene.
- * Demand of autonomy of states; separatist movements.

Positive factors:

Greater decentralisation.

Increased political consciousness.

Greater awakening among the marginalised, especially dalits, tribals and backward classes.

These emerging trends must receive attention.

What is to be done?

Jesus has shown us the way. He reaches out and touches the people in need. There was always a personal involvement.

Jesus teaches us through the parable of the Good Samaritan (Luke 10 : 30-37). The values depicted there are compassion and an awareness of the need of the person. His compassionate awareness is not blocked by selfish interests or pressures of other work. There is immediate personal response and then commitment to give further assistance, planning, financing and co-operating.

Compassionate awareness and loving care characterise the best of church-related health care. We have to extend that care to persons with disabilities. I have often wondered why the church has not been more involved in the problem of people with disabilities. Jesus' Healing Ministry (as recorded in the gospels) was mainly with people with disabilities.

The compassionate care must be made relevant to today's needs and possibilities. We need to think of the individual, the family and the community. There is need for community awareness and action. The community must become fully involved to ensure that the person with disability is fully integrated into the society.

There are many ethical issues too: *macro-ethical*, involving policies and *micro-ethical*, concerning individuals.

Macro-ethical issues in disabilities involve access of the disabled to public services, integration in schools, opportunities to develop full potential and many others. Have we looked at our policies critically and ethically? Are they enabling or further disabling?

Our policies should ensure

- * Service of persons, with equal opportunity and dignity for all;
- * Wholistic approach, relating to whole person, in the whole community, in the environment;
- * Preferential option for the poor and the disadvantaged.

Human dignity is important for all, whether the person has a handicap or not. Persons with disabilities are often treated as lesser beings.

People have to be viewed as a whole. Not just as a whole individual person either, but viewed as an integral part of the family and the community, with a network of relationships—to their families and friends, their work and their social milieu.

Our responses are very often limited. We think that we have done a lot when we have reserved two or three percent jobs for persons with disabilities. A few days ago, I met Mr. Lazar. He is polio affected and has paralysis of one complete lower limb. He asked a question: by employing a person with paralysis as a telephone operator, are we helping the person

to develop further or to inhibit him from developing his full potential? Lazar did not want to be trapped. He became an animator in the Diocesan Social Service Society. I asked him what he wanted. He had no hesitation: 'I want to empower people. I want to remove the disabilities of the able-bodied'.

The Lazars of the world want to be integrated, not segregated; they want equal opportunities, not pity.



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